

**Mother Knows Best: Gastrostomy feeding in disabled
children - professional and parental discourses**

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I would like to dedicate this thesis to all the women who took part in the gastrostomy study, particularly those who agreed to be interviewed and allowed me a glimpse of their lives; their loves, their hates, their delights and frustrations. I was struck by their struggle to be 'good' mothers and do the 'right' thing. I am indebted to them for their time and patience. I would also like to thank my supervisors, Graham Scambler and Erica Burman for their support and direction. Finally I would like to thank friends and family for their support and encouragement during the writing of the thesis.

Abstract

Mother Knows Best: Gastrostomy feeding in disabled children - professional and parental discourses

This thesis explores professional and parental discourses in relation to gastrostomy feeding technologies. Drawing on resources from feminist poststructuralism as a rationale for interpreting women's accounts, it examines how these ideas can lend themselves to the study of parenting and feeding. Current clinical and research arenas bring health care providers, children and their families to make decisions about children's feeding. A prevalent medical discourse in feeding disabled children revolves around malnourishment and poor growth, prompting a perception of the need for a gastrostomy feeding tube.

Interviews with 22 mothers, between 1998 and 2001, formed part of an externally funded evaluation of gastrostomy feeding which the author was employed to co-ordinate. The author presents a deconstruction of the research study to explore how researchers mediate between different clinical and research discourses, and analyses how the subsequent political and ethical issues impact on children and their families.

Women's accounts are analysed as constructing tube feeding as an intervention that either transforms their child by rendering her as 'other', or transforms their way of relating to the child, represented through oral feeding. Tube feeding was also constructed as an infringement of the child's rights to be involved and participate in social arenas, also associated with oral feeding. Both parents and clinicians constructed feeding decisions in terms of the child's best interests but, informed by competing and contradictory discourses, arrived at different conclusions about children's care. Parental accounts are analysed in terms of complex cultural-political overdeterminations between discourses of mothering, children's rights and normative child development.

This analysis suggests that the clinical focus on weight-gain may underestimate women's concerns and has implications for how services support families. Drawing on

reflexive methodological debates, the author highlights the needs and responses of researchers and clinicians, and indicates how these could be better addressed.

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1. Introduction: It's only natural

On entering the study

This thesis was carried out as part of a wider project set up to evaluate the medical, psychosocial and economic aspects of gastrostomy feeding interventions in children with developmental disabilities. The aim of the study was to identify the predictors of positive outcome of gastrostomy tube feeding¹ for children and their families. It was set up by a group of clinicians specialising in the management of children with feeding difficulties at a major paediatric hospital. The clinicians were also responsible for monitoring the progress of the study by forming a steering group. The steering group comprised two psychologists, two paediatric neurologists, a dietician and a surgeon. I was employed to co-ordinate a multi-disciplinary research team and oversee data collection and analysis. The research therefore, was set up to identify the costs and benefits of gastrostomy tube feeding to children and their families.

The study was funded by the NHS Executive Research and Development Programme for People with Physical and Complex Disabilities with a grant of a quarter of a million pounds for a period of 42 months (April 1998-October 2001), and was later extended to September 2002. The grant funded a number of part-time research staff, many of whom were already employed by the hospital, including a specialist paediatric registrar, a speech and language therapist, a dietician, a psychology research assistant, a health economist, and my post as research co-ordinator, reflecting the nature and type of assessments to be carried out.

The research design was an experimental controlled study comparing children and their families on a number of medical and psychological outcome measures both pre and post surgery.

¹ A gastrostomy tube is a feeding device that is surgically placed into the child's stomach. The child is then fed through the tube with formula feeds obtained on prescription.

A qualitative component (i.e. in-depth qualitative interviews) was also included on the recommendation of the funding body, and involved a sub-sample of patients, who were also participating in the clinical evaluation. This was in recognition that standardised psychosocial assessments (e.g. tools designed to measure stress and coping) may not reflect parental experiences as the following comment, made by one of the reviewers of the research proposal, illustrated:

My biggest criticism of the study as currently proposed is that it does not seem to include any qualitative data. Measurement instruments with numerical parameters are all very well and essential in this kind of work, but they often lack the vital human flavour of what the experience meant to the parents. A few sentences from a parent can be vastly more revealing to a critical audience than any number of statistical tests. [Anonymous referee]

As a result, the Commissioning Advisory group suggested that:

The aims of the study might be better addressed through good qualitative interviews before and after the gastrostomy, rather than using four different psychosocial indices and collecting data on 'other family variables'.

In addition to my role as project co-ordinator, I was employed to develop the qualitative interview study. My aim was to explore the type of issues families take into account when making a decision about whether their child should have gastrostomy surgery and identify ways of supporting families. I proposed to interview families before and after surgery (the aims are detailed in appendix 1).

Data from the clinical evaluation will not be presented in this thesis except for the purpose of illustration. However, I have described the background to the study and its rationale in appendix 2. Although I had originally intended to submit a thesis based on the interview study alone, the conflicts and contradictions that I faced working across different paradigms became a principle component of my PhD thesis. It should be noted that the interview study was not designed to be a separate study per se. Due to the lack of personnel with experience in qualitative research in the department where I was employed, it was decided that the best way of obtaining supervision for the interview study was if I enrolled as a PhD student. The different dimensions of the evaluation will be referred to as the 'clinical evaluation' to describe the quantitative, clinical and

research outcomes (see figure 1, appendix 2), and the 'interview study' (see appendix 1). In doing this it is not my intention to create a false dichotomy between quantitative and qualitative research, I am merely describing how I entered the research study, which also defined my role and remit.

In addition to the interview study I also highlight some of the contradictions researchers encounter when working across different research paradigms. I present a reflexive analysis of my role and experiences in executing the clinical evaluation. I reflect on my own institutional positioning in directing an externally funded research project while conducting an interview study, constituted as part of a PhD thesis with an explicitly feminist orientation, 'piggy-backed' onto a major evaluation of feeding technologies. Research takes place within institutions which structure or frame the research we do. I describe the different contexts, which both inform, and have implications for, the conduct of research and clinical practice. A number of competing, and sometimes contradictory, discourses in the execution of research within a clinical setting are identified and I look at how they overlap in both productive and unproductive ways. This process of reflection will cast light on how clinical, ethical and methodological issues intersect and the attendant consequences for research practice. I will view my institutional positioning and subsequent conflicts as a resource for a 'reflexive' analysis.

This process of reflection will reveal the interplay of discourses underlying different research approaches within a clinical context. I argue that although the importance of qualitative research in evaluating health care interventions is increasingly accepted, there is an assumption that research methods are complementary and additive (Craig, 1996; Burman, 1997). I aim to illustrate that the notion of the researcher crafting her trade with the help of a methods 'toolkit' is not unproblematic and highlight some of the tensions researchers may encounter when operating within and across different research discourses.

Impressions on entering the field

When I first took up my post as co-ordinator of the gastrostomy study I partly identified with women who did not want their child to have a gastrostomy tube. After all 'it's only natural.' Further, a number of clinicians had begun to discuss the challenges of working with families who were opposed to gastrostomy feeding interventions and the role of child protection proceedings. One family, in particular, became the topic of a case study because of a concern that the child was 'at risk' (i.e. severely malnourished). Clinicians attempted to rationalise parental opposition to the procedure as their inability to come to terms with their child's feeding difficulties and, ultimately, disability.

When details of the child's weight were presented to other health care professionals, the reaction was one of shock and disapproval. The family were described in ways which portrayed them as dysfunctional, in particular, their numerous attempts at soliciting alternative therapies, the number and extent of which were listed and taken as further evidence of their 'deviant' behaviour rather than the actions of caring parents. Those clinicians that were seen to respect the parent's decision not to pursue gastrostomy surgery were seen as 'colluding' with the family.

As if to confirm the strength of parental opposition to gastrostomy feeding, one of the doctors mentioned that a group calling themselves 'women against gastrostomy' had recently been established in the community. There was also talk of families who allegedly moved from borough to borough in order to disengage from the community services that were 'pushing' them towards the idea of gastrostomy feeding. It is perhaps worth mentioning that I was unable to establish whether the women's group did actually exist, or whether this was merely a rumour. Further, it is clear that the doctors were talking about extremes, as it would seem most families do not simply 'disappear' when they disagree with their doctors.

The example serves to illustrate the extent of professional anxiety around the issue of gastrostomy feeding in disabled children. Inaction is perhaps anathema to medical culture given professionals have a duty of care to minimise suffering and further the

welfare of the child (RCPCH, 1997). This professional anxiety mirrored my own as I considered how I might negotiate an interview with families opposed to, or unsure about, gastrostomy feeding interventions. As the co-ordinator of a study designed to generate the evidence needed to prove that gastrostomy feeding was beneficial, I wondered whether parents would be willing to talk to me and how they would perceive my role (I discuss this in chapter 5).

Some time into the study, I began to wonder why, if a gastrostomy was beneficial and could help with feeding and growth, mothers were so unreceptive to the initial recommendation of a feeding tube. I don't have children and I don't have experience of feeding a disabled child, or even of feeding a reluctant child, but I could see how a feeding tube might relieve some of the stress around feeding. Given children often had other things inserted into their bodies such as grommets, I wondered in what way a gastrostomy was different, or was it?

It was this apparent resistance to tube feeding that informed my research questions and analysis and helped me to reflect on why something potentially helpful (the gastrostomy) was such a difficult issue for families. Put another way, what was it about a family's refusal to accept clinical recommendations that caused the doctors to engage in 'myths' about families moving boroughs and disappearing in order to avoid engaging with the clinical services? This led me to reflect on the divergent viewpoints held between some parents and professionals about what constitutes the child's best interests, and why, despite apparently compelling 'scientific evidence' that a child needed a gastrostomy, parents disagreed with the clinical evidence presented to them. It is my intention to explore this paradox of competing and contradictory discourses which challenge the status of expert knowledge leaving the burden of responsibility for decision making on parents, and in particular, women as mothers.

Deconstructing the natural

The women drew on strong normalising discourses in their constructions of mothering, feeding, and child development echoing my own preconceptions about whether a

feeding tube was natural. An opposition between the 'natural' and the 'social' was a central organising feature of parental constructions of feeding technologies. Their accounts represented feeding interventions as having the potential to transform their child, and render them 'other' (discussed in chapters 7-10), or transform their way of relating to their child which was constructed through the medium of feeding (discussed in chapter 6). Women's accounts of tube feeding therefore reflected an anxiety about transformation and change. I argue that the 'normal/abnormal' dichotomy is unhelpful and identify tensions and contradictions associated with its use in the context of infant feeding and feeding technologies. Appeals to the 'natural' therefore, provide a further backdrop to my analysis.

Saraga (1998:21) notes the importance of challenging 'it's only natural' type explanations, suggesting the naturalisation of social constructs serves to privilege certain kinds of knowledge or representation by appealing to a higher rationality or universality. For if something is natural, we can't change it. The naturalisation of the social therefore involves strong claims to truth. As Weedon, (1989:4) states:

The appeal to the natural is one of the most powerful aspects of common sense thinking, but it is a way of understanding social relations which denies history and the possibility of change for the future.

Appeals to nature have been used in constructions of women's reproduction, sexuality and mothering and reinforce the biological. The converse of this is that when women do not fulfill their biological destinies, they are seen as unnatural. Conceiving a child outside of prescribed age limits, or outside of a heterosexual relationship (for example, lesbian, virgin, older and teenage mothers) results in the vilification of women for going against nature. The natural is bounded and has limits with real consequences for those who fall outside.

The nature argument has also been used to justify gender inequalities based on women's inferior bodies (the weaker sex), or inferior minds - raging hormones ruled by their biology - (Gatens, 1996:50). Shilling (1997) suggests these views became more predominant in the eighteenth century as science took over from religion as the arbiter of knowledge. The lack of equality between the sexes and races posed a moral problem

for the visionaries of the Enlightenment (informed by a philosophy of reason and progress). Scientific evidence therefore was marshalled to justify the subordination of women and people from other races, rendering them inferior, usually on the basis of their biology. Social constructionists are therefore wary of explanations that appeal to nature because they mask relations of power and domination. In attending to women's accounts of self and relationships with others, I locate those discourses within their historical context. For if knowledge can be shown to be local, temporal and contingent, thereby problematising notions of universality, this may provide a number of alternate subject positions for women to occupy within dominant discourses of mothering.

Our normal thing is to eat, isn't it?

The normalisation of food and eating fails to attend to the way people, and women in particular, regulate their own intake of food, and that of others. For example, 48% of women between the ages of 25-35 are reported to be on a restricted diet and 20% of young women say they diet all or most of the time (Steiner, 2002:30). Some authors have gone as far as to suggest that dieting and diet mentality can be regarded as 'normative, both descriptively and prescriptively' (Malson, 1995:87 quoting Polivy and Herman, 1987). Further, increasing numbers of women experience food-related problems, anorexia and bulimia.

Recently a WHO study reported that 18% of the world's population is now obese and obesity is fast becoming a bigger problem than famine and under-nutrition (*The Guardian*, 23 Feb 2002). Concerns are such that a Leader in the *Guardian* (24 April, 2003) warned: 'obesity is quickly eclipsing tobacco as the number one threat to public health'. Increasingly people (in the Western world) are resorting to surgical methods to deal with body shape and weight, for example, tummy stapling, lipo-suction, and the wiring of jaws. It has been estimated that obesity leads to 30,000 premature deaths per year in the UK from heart disease and diabetes (*The Guardian*, 24 April 2003). In response to the public health threat, the WHO suggested restrictions on sugar consumption, although this met with strong opposition from the sugar and soft food and drinks industries. What was disturbing, perhaps, was the way lobbyists in the US

applied pressure to persuade the WHO to rescind the advice to restrict sugar consumption to 10% of calories consumed by threatening to withdraw funds to the tune of £260 million, the sum the US pays annually to the organisation (Boseley, 2003). This example illustrates that, far from being 'natural', food is highly political and contested.

With respect to children, although a high proportion of children with neuro-developmental disabilities experience specific types of feeding difficulties, in the population generally there are significant numbers of children who fail to thrive for non-organic reasons, suggesting feeding difficulties are more widespread (Heptinstall et al., 1987). An ever increasing number of children are said to suffer from food allergies. All these examples attest to the fact that eating may not be as routine as assumed.

Natural equals good equals better

The natural is increasingly equated with better and tends now to be associated with middle class values. 'Natural parenting' is very much an ethos promoted by the National Childbirth Trust and Active Birth Centres. The child's natural immunity is invoked as an argument against immunisation for example. Organic food is seen as natural and therefore better, although prohibitively expensive for many families. There is also a move toward a natural death. What these movements allude to is a romantic notion of allowing nature to take its course. Conversely, ageing, death, sickness and pain are simultaneously regarded as unnatural and something we should avoid or control through medical interventions. As Leysen (1996:173) states: 'The message of popular culture is to be fit, healthy and active at whatever age or stage in life'.

Ironically, 'nature' is also responsible to some extent for many disabling conditions, for example children born with rare diseases and life-limiting conditions. There are times then, when the natural does not equate with good. This is aptly illustrated in the example of a family who fed their child a restricted, raw, vegan diet reported in a national newspaper after which the child died of malnutrition (*The Guardian*, 15

September 2001). The parents' rationale for the diet was that they had to 'follow the law of nature' despite repeated medical advice to widen the child's diet.

A second example relates to a woman with HIV and concerns surrounding the risk of transmission to her baby through breastfeeding. A London Borough Council attempted to obtain a court order for the baby to be tested for HIV against the parent's wishes. The Council was hoping to dissuade the mother from feeding if the baby tested negative. If the baby tested positive the Council wanted to carry out treatment for HIV. The father, an alternative health practitioner, reserved the right to make decisions about the child and did not want conventional drug treatment for HIV to be administered. The court order authorised a test, but not treatment. The judge resolved that the law 'cannot come between the baby and the breast' (Dyer, 1999). I intend to problematise the notion that feeding is fundamental to the mother-child relationship by suggesting the mother-child dyad is an artefact of a developmental discourse in chapter 6.

The above example not only considers whether nature might be harmful, but raises issues about the complex relationship between women's bodies, infant feeding, the rights of children and their parents, and the role of the state. Women in developing countries for example, have been exposed to conflicting messages about infant feeding as a result of the marketing of breast milk substitutes by companies such as Nestlé, and campaigns which seek to (re)promote breastfeeding to counter company propaganda. Avoiding breastfeeding is the official recommendation for women who test positive for HIV² and pressure is brought to bear on women who choose to disregard this advice (Sachs, 2000). I will discuss the issue of contradictory advice in relation to feeding practices, particularly in relation to disabled children, in chapter 4.

The role of child protection proceedings in relation to gastrostomy feeding remains a sensitive issue but left me to reflect on what stance feminists might adopt in relation to the role of the courts and infant feeding. One clinician, for example, remarked that if the children were not disabled there would be an outcry against such professional 'complacency' at the apparent level of 'neglect' (defined as a child grossly underweight

² Personal communication with Dr R. Miller, Reader in Clinical Infection, University College London and Camden Primary Care Trust.

compared with normative standards). As far as I am aware, child protection proceedings have not been used in relation to gastrostomy and disabled children. However, perhaps this raises the issue of whether disabled children have different 'rights' to be 'protected'. This illustrates some of the complexities involved in the notion of protection and ethics of care and indicates the difficulty of adopting a unitary position in the face of contradictory discourses about the rights of children and parents. I elaborate on this difficulty, and its varieties of forms and relations, throughout this thesis.

So far I have illustrated that nutrition is no longer mainly or simply a matter for individual choice but is one of public concern and involves the state in increasing surveillance and regulation of dietary habits leaving individuals to 'freely' choose the 'right' kind of food. Within current social arrangements however, women are held individually responsible for ensuring children and families receive adequate and appropriate nutrition (Department of Health, 1999). As such, mothers constitute an 'instrument in the exercise of government' (Nettleton, 1991:101). This raises questions about the extent to which the state should, and indeed does, intervene to regulate children's diets considered to be inadequate, harmful or merely unhealthy.

Research into Asian rickets in the UK was initially attributed to inadequate diet and deficiency of vitamin D. A number of competing explanations pointed to the lack of exposure to ultra-violet light due to poor housing and, the confinement of women indoors, partly due to fears of racial attacks (Helman, 1994; Pfeffer and Moynihan, 1996). The tendency to attribute problems specifically to particular social classes and cultures where these are marginalised, and, subsequently problematised, again fails to look at behaviour in its wider social, political and economic contexts (Ahmad, 1993). Advice about nutritional standards therefore needs to be taken in the context of economic resources. I draw on the Foucauldian concepts of the 'technologies of the self' and 'governmentality' (Foucault, 1991;1982;1980; Rose, 1990;1989) and their relevance to our understandings of choice, risk and surveillance in chapter 6 and throughout the thesis.

Food then says something about an individual's lifestyle and material resources although the meanings attached to food preferences vary historically and culturally. Lentils and brown bread, while viewed as healthy by those advocating an alternative food lifestyle, are associated with rationing, poverty, or war time privation by older, working class people. The idea of vegetarianism as a lifestyle choice may be puzzling to those who do not have a choice about whether to eat meat. Food is not only invested with moral meaning (i.e. what type of food is and isn't acceptable to eat and to feed to children) but it is classed (obesity is more prevalent in the lower social classes and healthy food tends to cost more), raced (as illustrated by the Asian Rickets campaign) and, gendered (I was once told marmalade was a man's food, men drink beer etc; in certain cultures women only eat after men have eaten, or are not allowed to prepare food because of menstruation). Specific types of food, the preparation and eating of meals, who cooks and why, who eats what and why, and who sits at the meal table and who doesn't, are all invested with meaning. This was apparent in women's accounts of feeding.

Paving the way: Conceptual frameworks and outline of the thesis

This thesis is divided into 12 chapters that describe the multiple and contradictory discourses at play when families seek medical advice on the management of their children's feeding. I explore how discourses of mothering, 'normal' child development, disability and children's rights intersect with medical and feminist/research discourses, and the different subject positionings available to researchers when mediating between the different discourses. I now move on to discuss my theoretical frameworks and the outline of the thesis.

My theoretical approach is primarily focussed on health evaluation, policy and practice within the NHS. To this end I draw on the following theoretical and disciplinary resources (which I elaborate further in chapter 2) to develop my arguments: medical sociology, psychology, psychoanalysis and, feminist poststructuralism, including discourse, deconstruction and reflexivity. The thesis is in some respects 'cross and multi-disciplinary'. I'm drawing on these resources for conceptual tools to reflect on

some of the tensions of working across contradictory paradigms in order to enhance our understanding of the process of academic research. Feminist analyses of the social construction of subjectivity, for example, have drawn on poststructuralist theorists, such as Foucault, in order to understand the dominant constructions of motherhood and the way women have come to participate in the surveillance of their mothering (Walkerdine and Lucey, 1989). I use discourse and deconstruction in order to identify particular perspectives in relation to feeding and parenting and make broader connections with social and cultural practices (Burman and Parker, 1993). Weedon (1989:136) aptly describes the value of such an approach:

The principles of feminist poststructuralism can be applied to all discursive practices as a way of analysing how they are structured, what power relations they produce and reproduce, where there are resistances and where we might look for weak points more open to challenge and transformation.

In drawing on these approaches for conceptual tools I intend to challenge dominant scientific discourses and expose contradictions in expert knowledge. Chapters 3 and 4 provide parts of the conceptual apparatus where I demonstrate how medical and psychological discourses construct the problem of children's feeding and their clinical management. Disabled children and their families are defined as objects of knowledge and are ultimately governed by that knowledge (Dayle and McIntyre, 2003). I also provide examples where parents resist expert knowledge.

Given the level of anxiety around feeding disabled children, both parental and professional, and the way anxiety becomes embodied within institutionalised discourse, and given my own anxiety about my role within the research enterprise, it seems apposite to theorise the role of anxiety and emotions in the conduct of research. I draw on psychoanalytical resources to understand how emotions function in fieldwork, and in particular, those that arise as a result of forming relationships with research participants and in relation to the types of conflicting accountabilities that researchers encounter as part of the institutionalised process of research. Institutional practices give rise to contradictions, both undesirable and unpredictable. I document how these conflicts come about and identify what mechanisms are in place, if any, to resolve them. I discuss these issues in chapters 4 and 5.

In chapter 3 I include an overview of the medical and psychological literature in relation to gastrostomy feeding which formed part of a report to funders. I explore how researchers construct and represent knowledge through the discursive practice of 'reviewing the literature'. I demonstrate that literature reviews, far from reflecting an objective state of facts involve 'rhetorical procedures' that 'textually disembodify' knowledge (Aldridge, 1993:54). The narrative, content and form are typical of texts constituted within a medical genre. The narrative generates an expectation that the proposed study will provide decisive evidence on the costs and benefits of gastrostomy feeding interventions by crafting an argument for the need for systematic, rather than, as currently constituted anecdotal evidence.

The question of what we can know, how we can know it and make judgements about the relevance of particular knowledges is relevant to feminists. Within the NHS, such decisions are framed within the discourse of Evidence Based Medicine (EBM), characterised by a commitment to Enlightenment rationality and positivism and informed by a hierarchical, masculinist discourse (Childs and Ellison, 2000). In chapter 4, I mount a critique of science and medicine by exposing clinical practice as an 'interpretive act' (Greenhalgh, 1999). I demonstrate how discourses of evidence both subvert, and are subverted by, hierarchies of power which are not only gendered, but have ethical consequences for the clinical management of children and their parents.

I continue the theme of ethics in chapter 5 where I address the issue of research practice, ethics and emotions in the context of researcher positioning within institutions and highlight the conflicts in medical care that is both constituted as a science and as a caring profession (Alderson, 1990). I draw on the feminist ethics literature as a counterpoint to biomedical ethics, which governs research practice in medical schools. I argue that far from protecting participants, bioethics represents a male dominated ethics that serves the interests of a male dominated science by protecting the academy and failing to address issues of power and control in the research enterprise. I demonstrate that the conflation of research with care sets up particular subject positions for researchers that may be inimical to feminist goals of egalitarian research practices. I illustrate how dominant research discourses of objectivity, legitimated by a biomedical ethics, script out emotions from the research enterprise and deny their existence in the

conduct of research and the production of knowledge. I highlight the role of institutional psychic defense mechanisms in dealing with emotions and at the same time identify a lack of support mechanisms for researchers who are left to manage emotional conflicts. I also discuss how particular methods raise issues about the ethics of (mis)representation of women's experiences.

I move on to examine women's accounts of feeding in chapter 6, where I explore the discursive practice of infant feeding. I demonstrate, with reference to three women in particular, how they construct feeding as a 'special time' drawing on the discourse of the 'sensitive' mother. I argue that women's domestic labour, constituted through play, has been transformed into a pedagogy which serves to regulate women and children and which serves to produce reasonable, democratic citizens (Walkerdine and Lucey, 1989). I highlight how the prevailing discourses of mothering reflect predominantly white, middle class norms, such that women whose parenting practices do not meet with the normative standards of sensitive parenting are pathologised.

I continue this theme in chapter 7 where I explore how constructions of the idealised child and the cultural values of autonomy and independence inform women's parenting practices in relation to feeding. I argue that women construct feeding as part of the project towards cultivating independence in children. Children's rights to participate, to communicate and be involved, feature strongly in women's constructions of gastrostomy feeding as a potentially exclusionary practice infringing the rights of the child. I suggest that involvement and participation, constructed through feeding and mealtimes, are parts of the process of preparing children for citizenship. However I also give examples of institutional practices that infringe children's and parents' rights by segregating and, therefore, regulating gastrostomy fed children. I demonstrate that the discourse of rights, informed by liberal individualism, is inherently contradictory. Not only does the rights discourse pit the rights of children against those of women, but also constructs particular groups of women and children as having fewer rights than others.

I continue the link between mother, child and community in chapter 8 where I discuss the woman's role in producing democratic citizens. Developmental discourses of child-

centredness construct force as harmful to children's development and ultimately, a threat to democracy. These discourses construct the use of force as undesirable and deviant. Women who resort to force or coercion are branded as insensitive mothers. However, women's accounts illustrate that force is an inevitable aspect of feeding disabled children thereby subverting the idea of a 'naturalised' form of feeding. Their accounts bring into stark relief the contradictions between discourses of the sensitive mother, normative development and the rights of the child, as coercion becomes an inevitable and contradictory aspect of a caring discourse.

In chapter 9 I look at how parental accounts of feeding technologies construct the child as other. Women's different constructions of feeding technologies distinguished between the gastrostomy as an object, a hole in the stomach, as well as a feeding practice. Parental anxieties about feeding technologies related to the way 'tubes' threatened to transform the child reflecting an ambivalence that the potential for change can generate suggesting 'food and eating question bodies and identities' (Probyn, 2000:32). I draw on Kristeva's theory of abjection to explain anxieties about difference and the emotions of revulsion and disgust. I argue that while postmodern attempts to privilege the cultural and aesthetic can provide a useful resource to disrupt the dominant constructions of the biomedical body, taken outside of the material and economic contexts that discursively produce bodies, these approaches fail to theorise why particular bodies are valued or discriminated against.

In chapter 10 I explore notions of difference further in relation to theories of stigma and deviance. I argue that not only do theories of stigma individualise disability, but also fail to adequately theorise the effects of race, class and gender. In particular, stigma theories fail to acknowledge the link between women and state and their role as transmitters of culture and identity through the bearing and rearing of children (Yuval-Davis, 1997). Gender relations therefore lie at the heart of cultural constructions of identity. I argue that the notion of stigma needs to be discussed in the context of prevailing discourses that serve to bolster dominant groups which maintain their economic and social power through ideologies that serve to perpetuate discrimination based on the notion of difference.

In chapter 11 I examine how medical discourse constructs a link between women's reproductive capacity and their mental health. Here women reproduce the association between feeding children and their own mental well being. Psychological approaches to families with disabled children typically employ a stress reaction or loss paradigm where families are viewed as suffering from depression and an inability to cope. I argue that psychological tools designed to measure stress and coping are premised on a particular construction of subjectivity, that of the self-contained, agentic (masculine) individual typical of Anglo-US psychology, which reflects the cultural values of autonomy and independence. I argue that a focus on the mother-child dyad fails to acknowledge the material circumstances that would enable women to parent more effectively and leaves the most economically marginalised more likely to be branded as insensitive in their parenting practices. I discuss the role of guilt, blame and regret in women's accounts at not having established a feeding relationship. I argue that the personalisation of responsibility for children's feeding, and subsequent management, precludes a discussion of the socio-political context of mothering and obscures the wider issue of structural power relations in contributing to women's oppression.

In the final chapter I draw together some of the themes I have raised in relation to women, mothering, child development, children's rights and the role of expert knowledge in protecting the rights of individuals based on particular constructions of subjectivity. I argue that the contested status of evidence has implications for children's rights and protection. Increasingly expert witnesses are called to give evidence in trials only to be discredited, challenging the authority status of the expert. Within the climate of this apparent loss of confidence and increasing personalisation of risk, women are expected to make decisions about what is the best course of action for their child. I examine ways in which parents can be supported and problematise conventional approaches to support located within the rhetoric of rights and informed choice. I argue that the conflicting and contradictory nature of the rights discourse suggests that what constitutes the child's best interest is provisional, contestable and a matter for negotiation.

Audiences

This thesis will be of interest to a variety of audiences including health care professionals working with children and families with disabilities with a particular interest in feeding. The analysis presented will illuminate the structural and psychic investments in feeding and caring for non-disabled, as well as disabled children and will be of interest to a range of professionals with an interest in children's feeding. My exploration of relationships between researcher and researched, and the interface between the research enterprise and the clinical services will be of interest to researchers working within the health services, academics and commissioners of research. My exposé of contested knowledges will be of interest to feminists, those involved in medico-legal cases and the field of child protection and children's rights. The work is also of relevance to those wishing to reconfigure service delivery to children and their families. My conclusions point to the need to re-orient services with a greater emphasis on parental support than is currently available for many families. Finally, I hope the analysis offered here will be of interest to women facing decisions about the feeding management of their children.

2. Methodological approaches

Introduction

The construction of knowledge is a central issue for feminists, including who constructs knowledge, what kind of knowledge, for whom and to what purpose (Westkott, 1979). Criticisms of science as culturally gendered and raced have given rise to feminist revisions of science (eg. Hartstock, 1987; Haraway, 1990). Feminist critiques of science point to the way women have either been excluded from the research process, or their experiences devalued in relation to masculine norms (Wilkinson, 1986:9). In particular, feminists have questioned the dualisms inherent in scientific discourses (e.g. objective/subjective) which have resulted in the construction of categories of people defined as 'other than' and often 'inferior to' the recognised notion of the 'knowing subject' constructed as the universal (rational) male (Lykke and Braidotti, 1996:2). In the words of Cheek (2000:58) 'binary oppositions thus become analytical sites of ongoing struggle and contestation'.

Feminists have criticised research for misrepresenting women's experiences by seeking universal truths and denying the diversity of experience in terms of race, class, disability and sexuality (Maynard, 1994). For many feminists, postmodern approaches, underpinned by a rejection of grand narratives and an emphasis on diversity and difference, appeal for these reasons. I elaborate on the issues I have raised here throughout this chapter.

In order to situate the methodological approach I have chosen I discuss the 'crisis' of representation of women's experiences and claims to knowledge in relation to debates within academic feminism which have taken as their focus feminist epistemologies, methods, and power in research relationships (Stanley and Wise, 1990; Harding, 1986). I now present an overview of this chapter, the presentation of which is structured by a feminist epistemology, which draws on the distinction between epistemology, methodology and methods. In the next section I describe the analytical approaches I have adopted, drawing on insights from poststructuralism, and this is followed by a

discussion of whether there is a specifically feminist method. I do this by charting the narrative of earlier feminist debates as one about methods, to more recent concerns about how we represent women's experiences and understand the dynamics of power and emotions in research relationships and fieldwork settings. This leads onto a discussion of feminist reflexivity as a resource for theorising power and emotions. I then go on to discuss social constructionism as a key interpretive resource in analysing women's accounts of parenting and feeding and the use of discourse and deconstruction. This is followed by the methods section, which describes the technical aspects of the research, and includes details of the interview study, participants, recruitment, transcribing, and analysis.

Analytical approaches

In presenting the analytical approaches adopted I draw on the distinction some feminists have made (e.g. Stanley and Wise, 1990; Harding, 1987;1986), between epistemology, methodology and methods in the conduct of research. A research method is defined as a technique for gathering evidence or data such as interviews and observations. Methodology is a theory and analysis of research praxis, for example, a perspective or framework such as social constructionism. Epistemology is a theory of knowledge that raises questions about how knowledge is produced and legitimated. For Stanley and Wise (1990:26) epistemology raises questions about:

who can be a 'knower', what can be known, what constitutes and validates knowledge, and what the relationship is or should be between knowing and being.

They argue for the need to describe feminist research processes and translate epistemology into a set of workable behaviours, suggesting the following analytical resources: the researcher-researched relationship, emotion as a research experience, how researchers manage the accounts of the researcher-researched and, finally, how researchers address issues of power within the research process. I draw on this analytical framework in informing the conduct of research practice. Research relationships, power and emotions are explored using a critical feminist reflexivity and

are discussed in chapter 5. I am interpreting the topic of how researchers manage accounts as one of how we represent women's experiences. In doing this I draw on resources from poststructuralism including discourse, deconstruction and subjectivity in my analyses of women's accounts.

Feminist poststructuralism 'is a mode of knowledge production' which attends to 'theories of language, subjectivity, social processes and institutions' (Weedon, 1989: 40). A poststructuralist approach (discourse, deconstruction and a critical reflexivity) provides a useful framework for understanding the mechanisms of power, resistance, and the possibilities for change. I draw on discourse and deconstruction as a rationale for presenting women's accounts and professional practice. I use insights from Foucault (1991;1988;1982;1980), in particular the concepts of 'governmentality' and the 'technologies of the self', and explore how these ideas can lend themselves to the study of parenting, feeding and health care practices. I draw on a number of resources that have influenced my interest in Foucauldian ideas, namely Dayle and McIntyre's (2003) study of children's feeding programmes in Canada, and the work of Valerie Walkerdine (1990;1984), Walkerdine and Lucey, (1989), and Nikolas Rose (1990;1989).

Initially, I analysed the data using an inductive, thematic analysis but felt this approach did not go far enough in accounting for the reasons why parents described particular feeding practices as natural or unnatural (I discuss further limitations of inductivist approaches in the final chapter). I also needed a framework within which it was possible to understand professional and parental practices and began to appreciate the relevance of poststructural perspectives in relation to the concept of normalisation (Urwin, 1985).

Scientific knowledge of the population was amassed on an unprecedented scale in the eighteenth and nineteenth centuries, which served to establish norms based on the concept of a normal individual which then informed a range of 'governing practices' including medicine, law, social welfare and schooling (Walkerdine, 1990:19). Foucault (1988:18) referred to these bodies of expert knowledges as 'technologies of domination' - 'which determine the conduct of individuals and submit them to certain

ends or domination, an objectivising of the subject'. Surveillance was later replaced by technologies of the self which:

Permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (Foucault, 1988:18)

Foucault termed this 'invisible hand' of social regulation that governed human conduct governmentality and is discussed further in chapter 6.

Foucauldian approaches view language as constitutive, rather than descriptive, of mothering and infant feeding practices, and it is through language that particular subjectivities are constructed (O'Connor, 2002). The approach I am using can be contrasted with the microanalytical varieties of discourse more commonly associated with conversation analysis (Antaki et al., 2003).

I attend to the issue of power within research relationships using a critical feminist reflexivity with particular attention to my experiences of carrying out a clinical evaluation as a feminist within the context of a clinical service. Given that all knowledge is socially constructed, we need to cast a reflexive gaze at the context of research in order to deepen our understanding of how knowledge is produced, which also allows us to see what is left out of this process. Nightingale and Cromby (1999:5) argue that 'knowledge is inextricably linked to, and emerges as a product of, activity and purpose'. It is therefore important to describe research and clinical activities, and their purpose. In order to take the research a stage further and offer a deeper insight into the subject matter, I will use discourse and deconstruction to illuminate the different contexts within which the research was conducted and throw a reflexive gaze on clinical and research practice. In the same way the researcher-researched relationship comes under scrutiny, so the clinician-patient relationship, and ultimately clinical practice, becomes a resource for further analysis.

In discussing the clinical evaluation study, I reflect on some of the tensions of working across contradictory paradigms and highlight how contradictions and emotions function

in a fieldwork setting. I draw on discourses of feminist reflexivity to highlight the contradictory and fragmented nature of medical and research discourses. I demonstrate throughout the thesis how a reflexive approach to research can highlight the intersection of a number of clinical, ethical and methodological discourses with consequences for research and clinical practice. I do this through the medium of ‘**contexts**’ which form part of the conceptual apparatus of my analysis. My aim is to show how research creates different subject positions for both families and researchers. The contexts describe exemplars where feminist and scientific/research discourses intersect and overlap. These sites of intersection present the foci for a critical engagement and describe what happens to research relationships when dominant scientific discourses prevail.

In chapter 3, I discuss how medical and psychological discourses construct feeding in disabled children and their families through the discursive practice of reviewing the literature, which I demonstrate is a rhetorical accomplishment, to problematise common assumptions about the representation of knowledge. In chapter 4, I highlight the fragmented and contradictory nature of clinical and scientific discourses in relation to the different discursive frameworks that organise professional practice. In chapter 5, I discuss researcher positioning, ethics and emotions in order to highlight issues of power and subvert the researcher/researched binary. In chapter 11, I examine some of the assumptions underpinning a psychological tool that was used to measure stress and coping (see appendix 5) and argue that these tools bolster particular constructions of subjectivity based on the rational, unitary male subject.

Reflexivity, discourse and deconstruction as applied in this thesis are probably best described as approaches, or rationales, rather than constitutive of a prescriptive method. The appeal in adopting such an approach is aptly described by Opie (1992:59):

The principles underpinning a deconstructive analysis depend upon thinking of language as nontransparent, as deeply involved in ideology, paradox, contradiction and ephemerality.

Barry (1995:77) argues that deconstruction as a form of analysis is not synonymous with destruction; rather the deconstructive reading aims:

To produce disunity, to show that what had looked like unity and coherence actually contains contradictions and conflicts which the text cannot stabilise and contain.

In attending to these 'warring forces of signification' (Barry, 1995) I problematise the primacy of medical and research discourses and show how their claims cannot stand except through reference to other frameworks and conditions.

The narrative of this thesis, then, is from the standpoint of a feminist epistemology and the analysis is therefore theoretically driven. In terms of presentation in this thesis, the analysis of discourse happens in the theoretical framing in which the transcripts are situated and I intend to examine how discourses work in terms of institutional practices (Parker, 1992). I now go on to discuss whether there is a feminist method by providing an overview of debates within feminism, followed by a discussion of reflexivity.

Is there a feminist method?

Earlier debates in academic feminism focussed on the question of whether there is a specifically feminist method and the virtues of qualitative, as opposed to more quantified, approaches. Although the question of whether feminist research can be defined in terms of a specific method is very much debated, qualitative approaches that favour the local and experiential are often held to be feminist friendly (Bevan and Bevan, 1999). It is suggested that quantitative approaches are unable to address particular aspects of women's subjectivity. Standard tools that purport to measure variables such as attitudes, stress and coping, for example, not only pre-define, and therefore abstract, women's experiences, but leave little option other than to tick boxes in response to statements. Such approaches are deemed oppressive because they impose, or fix, meanings and constrain, or misrepresent, women's subjective experiences (Roberts, 1981). However, how we represent women's experiences is not

solely a matter of method, but also addresses how we analyse, write about and present our research findings (Wolf, 1996).

The emphasis on methods later refocused to one of how researchers dismantle power within research relationships and the potential for exploitation and appropriation of women's experiences. Oakley (1981:41), for example, suggested the best way of 'finding out about people' is when a non-hierarchical, reciprocal relationship is established between interviewer and interviewee, 'and when the interviewer is prepared to invest his or her own personal identity in the relationship'. Oakley was later criticised for failing to acknowledge that a more personable, friendly style did not guarantee immunity from exploitation (Finch, 1984; Ribbens, 1989). Debates about the dismantling of power were then reformulated to address the issue of how power functions arising from the different positionings of the researcher and researched in terms of social and economic location, including, class, race, and ethnicity, which I discuss later under 'critical reflexivity' (Wolf, 1996).

Experience and representation

The question of how we research and represent women's experience is of concern to feminists because 'power is intimately bound up with representation' (Gill, 1998:26). Claims to the authenticity of experience, its expression and denial, have powerful effects. Within debates about feminist epistemology, the issue of representation has been discussed in relation to feminist empiricism, standpoint theories and post modernism/post structuralism (Harding, 1986; Henwood et al., 1998).

The postmodern turn came about largely as a result of a failure of second wave feminism, dominated by predominantly white, middle class women, to theorise difference in relation to women's different social locations, thereby failing to reflect the interests of working class, black, lesbian, and disabled women. This led to a move away from treating women as a homogenous group with shared experiences to one that emphasised diversity and difference.

Stanley and Wise (1990:21) argue that although the category of woman is socially and politically constructed, the 'ontological' basis 'lies in a set of experiences rooted in the material world'. Despite the ontological fracturing implicit in the category 'woman', they suggest that women do share experiences, although these may differ. Standpoint theory (e.g. Harding, 1986;1987) has attempted to maintain a hold on the concept of woman and commonality in experience and takes as its basis the idea that women occupy a privileged vantage point from which to develop insider knowledge because of their experience of oppression: 'women's subjugated position provides the possibility of more complete and less perverse understandings' (Harding, 1986:26).

While the notion of standpoint(s) have been criticised for both essentialising women and for falling into the trap of relativism i.e. multiple standpoints (Gill, 1998), post-modern approaches have been criticised for their lack of commitment to political change (Scambler, 1998). Although Harding (1986:28) acknowledges the tensions between standpoint and postmodern perspectives, she argues the contradictory tendencies in these positions originate in mainstream epistemologies and philosophies of science, and not in feminist discourse.

If language constructs, rather than represents, reality then there is no such thing as 'raw' experience waiting to be captured by researchers that goes unmediated. Rather, experience comes into being in the way we represent it through language and theory. Weedon (1989:8) argues for theories that recognise the subjective meaning of experiences and which, can relate these to 'material social practices and the power relations which structure them'. This involves: 'understanding how particular social structures and processes create the conditions of existence which are at one and the same time both material and discursive'. Similarly, Wolf (1996) argues for the need to recognise multiple feminist and epistemological projects. It is within this framework that I will situate my analysis.

Feminist reflexivity: Trading places - compromising positions

Not long after I took up post as co-ordinator of the clinical evaluation a number of potential conflicts arising from my institutional positioning became apparent. Not only did the conflicts revolve around the difficulties of trying to carry out research rooted in different traditions and within the context of the institution of the hospital, but also I found myself increasingly performing an advocacy role on behalf of families. Further, as discussed in the introduction, given some clinicians had expressed concerns about parental refusal to accept the recommendation of a gastrostomy, and the possibility that child protection proceedings could be instigated against those families, I began to realise the potentially sensitive nature of interviewing women.

Given my responsibility for recruiting families into the clinical evaluation and for obtaining permission for additional medical tests and investigations for research purposes, I was concerned that this would further link me to the clinical service and influence how families viewed my role. My position was one of trying to appear neutral about the treatment intervention in order that families could talk frankly about their views, while at the same time fronting a project designed to provide the evidence needed to show gastrostomy feeding was indeed clinically effective. The conflicts and difficulties this institutional positioning presented forms part of the rationale for a reflexive enquiry.

Reflexivities

Feminists have questioned whether the removed-detached scientist model associated with positivism is an accurate description of research practice. For example, Sherif (1989) argues that 'bias' in the form of involvement enters the research at the point where the researcher defines the research question (if not before). Stanley and Wise (1983:153) have criticised the way research has been described as opposed to experienced and argue that a central feature of feminist research 'is to make the researcher and her consciousness the central focus of the research experience' (Stanley and Wise, 1983:49). They argue that the beliefs and assumptions of the researcher and

the way these influence the process of research should form part of any analysis. Harding (1987:9) echoes this sentiment:

Thus the researcher appears to us not as an invisible anonymous voice of authority, but as a real, historical individual with concrete, specific desires and interests.

Wilkinson, (1988:495) argues that a reflexive analysis 'entails continuous, critical examination of the practice/process of research to reveal its assumptions, values and biases'. Feminism then, poses a direct challenge to scientific discourse by emphasising the subjective experience of the researcher. It further challenges the traditional separation between researcher and researched by acknowledging that both play an active role in the construction of knowledge. The research relationship then becomes a matter for a reflexive enquiry (Wilkinson, 1988).

A feminist reflexivity is distinctive in its attention to issues of power within the research relationship (Burman, 1994c). This is contrasted with other uses of the term in the social sciences, for example: as a form of methodological audit trail (Seale, 1999); as a resource reflecting the role of the researcher in effecting change in action research (Hart and Bond, 1995), and as the practice of 'validating' data in some forms of discourse analysis (Potter, 1988).

Woolgar (1988:214) drawing on the work of Garfinkel (1967), distinguished between 'constitutive reflexivity' and 'benign introspection'. The latter being akin to what he termed 'field work confessions' - 'the 'inside story' on how the research was done'. Conversely, constitutive reflexivity relates to the instrumental role of researchers in constructing representations of knowledge: 'Members accounts are constituent features of the setting they make observable'. Whereas science bolsters the view of the researcher as the neutral, objective measuring instrument, reflexivity denies this distinction, seeing representation and object as intimately connected' (Woolgar, 1988:22).

Researchers hold powerful positions in setting research agendas and interpreting women's experiences. Feminist researchers are accountable to the women who take

part in the research and are committed to the analysis and transformation of power relations within the research relationship. A focus on the subjective experience of the researcher is the first step in the recognition of a diffusal of power, where appropriate, and the process of knowledge production becomes a central focus of the research enterprise (Stanley and Wise, 1990). Skeggs (1994:88), commenting on the importance of a critical reflexive enquiry suggests:

It can increase the specificity of analysis by providing an economic, institutional, social and discursive context. It can bring into question universalistic or homogenous theories which speak from a position of privilege.

I combine and alternate between the two forms of reflexivity discussed here. My use of the autobiographical voice serves to disrupt conventional scientific genres of writing.

Contexts

In order to enhance our understanding of research practice, I draw on a number of settings or 'contexts' within which the research was conducted and the consequences for researcher and researched. The contexts form part of the methodological approach.

I have chosen to describe a number of contexts which both inform, and have implications for, the conduct of research and clinical practice. In so doing I aim to identify a number of competing, and sometimes contradictory discourses in the execution of research within a clinical setting and examine how they overlap in both productive and unproductive ways. The process and context of academic study is a much under-researched area which needs to be theorised. In attending to both process and context, I highlight the constructed nature of research and clinical discourse. My examination of contexts is intended to expose the discursive construction of medical and psychological praxis in order to contribute to theoretical and methodological debates together with an understanding of policy issues which are discussed in the final chapter.

The contexts highlight issues that are often presented as unproblematic within biomedical and research discourses. The contexts pose a number of ethical concerns

about the conduct of research and clinical practice. I highlight situations where attempts to protect scientific/clinical integrity clash with feminist concerns about exploitation in research relationships and egalitarian research practices.

Researcher positioning in terms of outsider/insider has been discussed in relation to action research (Coghlan and Casey, 2001). The authors state that practitioners conduct insider research. However, I argue that researchers are always multiply positioned by discourses of class, race and gender for example, in addition to their institutional positioning, a theme I take up in chapter 5.

For the purpose of this thesis, a context is defined as a set of discursive practices that have a particular resonance for the way research or clinical practice is organised. A context may be based on a routine clinical activity, such as the taking of blood samples to monitor a child's health, or nutritional status, for example. Common to all contexts is the way discourses construct and constrain different subject positions for clinicians, researchers and participants. Willig (1999:149) suggests institutionalised power relations such as those between doctor and patient (or even researcher and researched) are reinforced when research is used to bolster 'the smooth running of the institutions which they serve'. The contexts therefore serve to highlight discursive practices and problematise the hegemony of scientific discourse.

The 'contexts' were informed by my experience of carrying out the research, steering group meetings and academic lectures, observations in clinics, reflections on research practice and clinical care, and conversations and interviews with parents. The contexts were described and documented in a research diary.

Social constructionism

A dominant theme identified in preliminary readings of the transcripts was a desire to maintain oral feeding which was seen as having a range of psychosocial effects for both child and family (Craig et al., 2003). There was a tendency for parents to privilege oral feeding as the 'norm' with 'normal' child and family associations, and gastrostomy feeding as something that problematised these associations.

As discussed in the introductory chapter, social constructionist perspectives have been put forward that throw into question appeals to nature which often mask relations of power and domination. These perspectives suggest that practices demarcated as unnatural render them outside the norm, deviant and other (Alldred, 1996). Discourses of the natural therefore are invoked to maintain positions of social and economic power and reinforce the status quo. Conversely, social constructionism recognises that experience is deeply embedded within social, cultural and historical practices which govern behaviour (Willig, 1999) and contrast with the biological determinism often associated with discourses of nature (Shilling, 1997). Hence social constructionism is used as a key interpretive resource in my analysis.

Discourse analysis

There are a variety of approaches in discourse analysis with different levels and styles of analysis but all have as a common theme the attention to the sensitivity and structuring effects of language (Burman and Parker, 1993:3):

In its various forms, discourse analysis offers a social account of subjectivity by attending to the linguistic resources by which the socio-political realm is produced and reproduced.

Parton and Marshall (1998:244) define discourse as:

Structures of knowledge claims and practices through which we understand, explain and decide things. In constituting agents, they also define obligations and determine the distribution of responsibilities and authorities for different categories of person, such as parents, children, social workers, doctors, lawyers and so on.

In this thesis I am going to use discourse to refer to the use of language as a social practice (Wood and Kroger, 2000) and to relate discourse to material forms of power. That is, I am going to highlight the wider political implications of particular discourses for women, children and practitioners in relation to debates about the rights of children and their parents, and use discourse as a critical tool to comment on 'the social processes which participate in the maintenance of structures of oppression' (Burman and Parker, 1993:9).

The practice of feeding a child is laden with symbolic cultural meaning. A social constructionist approach is concerned with the meanings parents attach to discursive practices, which also raises issues about ideology and power. Discourse analysis is also a useful tool because it can highlight the variability in the accounts women give which directly challenge traditional models of subjectivity based on the rational, unitary, male subject. Feminists have challenged this construction of the subject, arguing that individuals are positioned by a number of contradictory discursive positions governed by context (Gillies, 1999). Law (1999:119) defines discursive practices as:

Ways of talking, thinking, feeling and acting that, when enacted, serve to reinforce, reproduce, or support a given discourse and at the same time deny, disqualify or silence that which does not fit with that discourse.

The aim of the analysis was to understand the ways in which respondents construct different feeding practices and technologies. This was achieved by identifying the discursive meanings attached to tube and oral feeding and identifying the discourses that informed women's accounts. I used discourse analysis to identify particular perspectives in relation to feeding and parenting and to make broader connections with social and cultural practices. The approach adopted here aimed to render more comprehensible the apparently contradictory nature of women's accounts in terms of their own contradictory positionings within dominant constructions of mothering.

It should be noted that there is no strictly defined Foucauldian method of analysing discourse (Hook, 2001). The analysis I am presenting attends to women's identifications with different subject positions. In attending to women's accounts of mothering and feeding, I locate these discourses in their historical and cultural context in order to understand their 'material conditions of possibility' (Hook, 2001:526). I also draw on other texts which offer insights into mothering and feeding, such as those offering child-care advice for example, in order to make broader connections with contemporary debates about mothering, feeding, and the rights of children and their families. As such I move beyond the text in my analysis as my interest is less concerned with the internal workings of the text than with identifying material forms of power in discursive practices and identifying those who benefit/do not benefit from the mobilisation of a given discourse (Hook, 2001:532). This is clearly demonstrated with

regard to the discursive practices involved in the clinical management of children, for example growth monitoring, the taking of blood samples and the way women are observed and video-recorded while feeding children. I draw on these discursive resources for my analysis.

In order to understand the significance of these practices it is important to examine how medical discourse constructs women and children as objects of a feeding discourse. This is described in the next chapter and forms part of the rationale for a deconstructive reading. I continue with this approach in chapter 4 where I illustrate the fragmented and contradictory nature of medical discourse. The importance of exposing the contradictions in expert knowledges has significance for the status of evidence, and, ultimately, has implications for how we define and protect children deemed to be 'at risk'. This is discussed in the final chapter in relation to children's rights.

Psychoanalytical discourses

Bingley (2002:220) suggests reflective practice can be used to denote 'the analysis of actions, processes, and feelings constituting practice'. I draw on insights from psychoanalysis in order to theorise the role of emotions in research and to account for some of the discourses I am using. Given the penetration of psychoanalytical ideas in everyday conversation, it is productive to explore the origins of terms in common usage which are often taken for granted; for example: 'identify with', 'splitting', 'project' and 'contain'. The popularisation of psychological discourse, once the domain of experts but increasingly accessible to lay people as reflected in their talk, has been termed the 'psy-complex' (Ingleby, 1985; Rose, 1985).

My interest in psychoanalysis is as a resource for reflecting on the interpersonal dynamics of research relationships and issues of power, positionality, similarity and difference (Bondi, 2003). In order to understand what happens in research relationships, Bondi draws on the concept of empathy and the processes of 'identification' (identifying with), and 'dis-identification' (identifying as other than). She suggests these processes are important in order to facilitate our understanding of other's experiences and our ability to empathise.

Finally, in demonstrating the intersubjectivity between researchers and participants I am seeking to challenge the detached, disinterested scientist model underpinned by a researcher/researched dualism. The binary structures embedded in foundationalist assumptions are predicated on a construction of researchers as 'empty vessels' waiting to 'soak up' the experiences of their participants and fails to reflect that relationships are dynamic, interactive and constantly impact on one another. Further, processing and understanding emotions in relational encounters 'involves working with ambiguity, inconsistencies and uncertainty' (Mersky, 2003), which subverts the view of the research process as linear, logical and sequential. I elaborate on the use of psychoanalytical resources in chapter 5.

Methods

This section describes the more 'technical' aspects of carrying out the interview study including the selection of participants, details of the interviews, transcription and analysis.

The Interview study

The aims of the interview study (as originally envisioned) are outlined in appendix 1. As previously stated, I broadened my analysis to offer an alternative perspective on parenting and feeding by drawing on insights from Foucault. However my original aims, to cast light on the issues for families making decisions about children's nutritional management, are still relevant.

Ethical approval was gained from the local research ethics committee. I recruited families into the study following their appointments with the surgeons in the outpatient clinic of the hospital where I was employed. I made it clear to all parents that they were not under any obligation to take part in the research. Where parents agreed to be interviewed, I usually interviewed them in their homes, before surgery unless they specifically asked to be interviewed at the hospital. The follow-up interviews took place between three and seven months after surgery. The interviews usually lasted between 45 and 90 minutes. In the 'pre' gastrostomy interview I obtained details about the child's history of feeding, the referral process and families' contact with the health

services, their views on tube feeding and information and support needs (see appendix 3). Post-operatively I asked parents to describe their experiences of tube feeding including any advantages or disadvantages, the impact on child and family in terms of quality of life, whether parents had made the right decision³, and information and support needs (see appendix 4). In addition, I obtained information about demographic details, including age and occupational status. All interviews were audio-recorded, transcribed and entered into a computer software programme (QSR NUDIST*Vivo 1.2) designed specifically for the coding and retrieval of qualitative data. Examples of material were indexed through linking documents, nodes and memos.

Selection of participants for interview

Thirty two parents were invited to participate in the interview study, either in person, or by letter, following their appointment with the surgeon to discuss their child's need for a gastrostomy. The mothers of 22 children agreed to be interviewed, sometimes with their partners, representing a response rate of 69%. Most were interviewed before and six months after surgery (17/22). Three mothers were interviewed on one occasion post surgery, and two were undecided about surgery and were interviewed once. The majority of families (17/22) also participated in the clinical evaluation. Parents were interviewed between 1998 and 2000. Within this time frame I selected participants in order to reflect a variety of experiences. A number of themes had already become apparent during a series of pilot interviews conducted with a view to constructing an 'attitude toward gastrostomy scale'⁴. The pilot study helped me to focus my research questions and sampling criteria. For example, did the experience of nasogastric tube feeding influence parental decisions to have a gastrostomy? If parents already had experience of a feeding tube did this make the decision to have a gastrostomy inserted in children any easier; was it just the case of replacing one type of tube with another, as doctors often described the procedure? Were constructions of gastrostomy different if the child had been adopted, given the adoptive parent may not have had the responsibility for feeding a child from birth? Did families' experiences of support vary as a function of residential location; city versus rural? Although I did not expect to

³The clinicians requested that I asked this question which I discuss in chapter 5.

⁴ The questionnaire was later abandoned.

answer these questions in any definitive way through the interview study, the examples describe how analytical categories are formed in the very early stages of data collection.

I subsequently selected parents along the following criteria: experience of nasogastric feeding, ethnicity, whether a child was adopted, residential location, and children's communicative ability, in addition to factors such as the child's age and diagnosis. I was also mindful of the measurement load on families and had to negotiate with them whether they could cope with the additional requirement of an interview on top of the questionnaire packs, and the medical assessments. I should state that within the context of a clinical evaluation, with a fixed timescale, it was not possible to adopt a purely purposive sampling strategy (Patton, 1990).

Reasons for non-participation

The main reason given for not participating in the interview study was the lack of free time, but from my field notes a number of other reasons were given which I elaborate on throughout this thesis, and in particular in chapter 5 where I describe the recruitment process in more detail:

- the mother did not feel she knew enough about gastrostomies to participate in an interview – 'don't know anything about it therefore can't talk about it';
- the mother appeared depressed. The parents said they didn't want to talk about the birth of their child and despite the reassurances I gave to them about only talking about areas they felt comfortable with, they were still reluctant to participate;
- the family were in the process of making a formal complaint against the hospital;
- the mother was very distressed stating that she felt rejected by the suggestion that her child had 'feeding difficulties'. She denied this was the case. When I stated that the research was also about looking at ways of supporting parents she was very defensive and almost took it as an accusation that she couldn't cope;
- the family were uncertain about whether the child needed a gastrostomy so did not want to talk about the procedure if it wasn't necessary;
- the child died;

- the foster mother was not prepared to participate in the research without the consent of the child's father who was opposed to gastrostomy feeding. The father was a single parent and was responsible for the care of a number of children in addition to his disabled son;
- one father, from an ethnic minority group, although happy to take part in the clinical evaluation, neither understood the purpose of the interview, nor had time to participate. The father owned a shop and worked every day. The mother spoke little English.

The reasons families gave for not taking part are illuminating and will be taken up, in part, later in the thesis.

Characteristics of participants

Children

All the children had feeding problems as a result of an underlying neurological impairment. Many had rare conditions and as such they represented the extreme end of the spectrum of disability, poor growth and health complications. The mean age of the children was 4 years 8 months (SD 3 years 6 months; range 13 months -13 years 3 months). There were 13 males and nine females. The majority of children had severe cerebral palsy (10/22) or syndromes with a chromosomal or genetic origin (10/22). The remainder (2/22) did not have a confirmed diagnosis. The children had a mixed range of abilities, although the vast majority of children were: non-verbal, could not walk and, were unable to sit independently, or self-feed, due to their age or disability.

I was unable to interview children directly due to their age, the severity of their communication and cognitive impairments, or because of my own lack of knowledge and expertise on how to communicate with non-verbal children. Four children were able to communicate non-verbally using sign language, a communication aid or other means and I elicited their views through their parents (this is discussed in chapter 10). Within the short time frame of the study it was not possible for me to gain the expertise needed to communicate with children, which would have been a project in itself.

Women

Four families were undecided about gastrostomy surgery at the time of the interview, two of which went ahead with the procedure some time later. Women's ages ranged from 29-49 years of age and the majority were in their thirties. Thirteen mothers (59%) were not employed. Of the nine women who worked, three described their occupation as secretarial/administrative, two were employed in skilled trades, two in the personal services, and two described their occupation as professional/managerial. Five out of the nine women worked part-time. The majority of women were living with a partner (82%), two women were lone parents and one lived with her mother. Women described their ethnicity as: White (68%), Black African (14%), Black Caribbean (4.5%), Chinese (4.5%), Pakistani (4.5%), or other ethnic grouping (4.5%).

However, I do not qualify the interview extracts according to these racialised and classed designations as I see no rationale for doing so. Squire (1989) problematises the focus on 'race' in terms of cultural differences, arguing that it de-politicises the term. Instead, I draw attention to issues of race and class as substantive topics throughout the thesis. I did not interview parents of children whose first language was not English because of the lack of funds for interpreting and translation costs. Finally I do not present data on women's sexuality or disability (I neither asked, nor was the information volunteered). There was nothing written in the hospital notes to suggest that any of the women were disabled.

Transcription

As the study was part of an externally funded project, I was fortunate enough to have administrative support, so I did not have to transcribe the interviews myself⁵. However, I listened to all the transcripts for accuracy of detail. The transcription of material emphasised readability (Moir, 1993). As my analytical focus aimed to identify the types of cultural and linguistic resources women draw on to account for their parenting

⁵ I would like to thank Vicki Peacey for transcribing the interviews.

practices and to relate these to broader ideological representations, I did not feel that an exhaustive system of notation (e.g. length of pauses) was necessary.

Finally I have not included the full interview transcripts as an appendix to this thesis, which is also customary within discourse analytic research, for reasons of confidentiality. Potter, (1988) for example, suggests discourse analysis must make the process of interpretation transparent and advises that as much text as possible be included in order to achieve this. However, I would argue that transparency is about framing the perspectives of the researcher and the context of research rather than including reams of transcript. It would have been difficult to include the transcripts given this was part of a funded project and subject to stipulations by ethics committees, for example, that all transcripts/data should be kept in locked draws etc. I had also agreed with parents that no one would have access to the transcripts other than an administrator and myself and that any details that might potentially identify the parents or child would be changed, hence the use of pseudonyms. In attempting to respond to these various concerns I have included large sections of transcripts, where relevant, for readers to see as much of the context of the interviews as possible.

In the text the transcripts are coded as follows: Where only one interview was carried out this is indicated by '1/1'; '1/2' denotes the pre-surgery interview; '2/2' denotes the post-surgery interview. 'G' (Gill) or 'M' (mother) or 'F' (father) or 'GM' (grandmother) indicates the speaker.

Whereas all the children's names have been substituted with a pseudonym I am aware that I have presented the women in terms of the children's 'mothers'; as such they are unnamed. It was not my intention to subsume the identities of mothers under those of their children and I recognise that my practice of referring to women in relation to their parenting status reproduces medical and child-centred discourses which position women as mothers rather than individuals in their own right. However, my practice of referring to women as mothers reflects how I entered the research study within the context of a children's hospital where parents generally define themselves in relation to their parenting status.

Analysing the transcripts

The analysis was iterative and arrived at through successive readings of the transcripts. Broad thematic categories were derived by focusing on the aims of the research and the topics covered in the interview schedule which were used to guide the analysis. Sections of text were selected on the basis of their relevance to mothering and feeding and analysed in order to attend to parental constructions of, and investments in, feeding and the dilemmatic nature of parenting (Billig, 1987). As such the extracts were chosen for a purpose and their significance reflects my aims rather than a specific property of a given extract. As Hollway (1989:36) states in relation to the selection of material: [the] 'significance is not a property of the extract, but of the work it is put to do'. The majority of excerpts presented are from women whose children did have a gastrostomy inserted. Particular attention was paid to the contradictory and changeable perspectives in women's talk (Potter and Wetherell, 2001). The analysis highlighted the extent of these contradictions and the points of overlap and contrast between the different ways of talking about feeding.

Although I used deconstruction as a rationale rather than a method per se, I adopted the framework identified by Boje (2001:23) This involved identifying any problematic dualities (i.e. where one was privileged while the other remained marginal or excluded). Cheek (2000:58) argues that, 'part of the deconstructive venture is to uncover such pairings and to expose their effects'. To this end I identified text where the terms 'normal', 'not normal', 'natural' or 'unnatural' or where notions of difference, or deviance, were implied in order to identify the different discursive constructions within women's accounts. I also attended to examples of hierarchical thinking that privileged particular narratives or constructions. This is apparent in chapter 3 where medical discourse constructs the aetiology of disability according to a cultural discourse, while ignoring the contribution of material factors. I used deviant case analysis to highlight variability in women's experience (Mays and Pope, 2000).

Conclusion

In this chapter I have discussed a variety of approaches to my analysis of material rooted in a feminist epistemology. I have argued that feminist poststructuralism, in attending to issues of power, allows us to theorise why women engage in different discursive practices vis-à-vis the mothering role, where there is resistance, and the potential for change. In this thesis I will highlight a range of rationales that women draw on to justify their decisions about children's feeding. I offer alternative perspectives on feeding relationships, intimacy, and power that subvert dominant medical constructions of children and their families. In the next chapter I show the discursive production of children with feeding difficulties and their families by means of a literature review. I argue that the act of reviewing the literature is a discursive practice involving a number of rhetorical strategies that serve to position researchers as experts.

3. Medical and psychological constructions of feeding, parenting and disability

Introduction

In this chapter I highlight how medical and psychological discourses construct the problem of children's feeding difficulties by means of a literature review. The review formed part of the final report to the funding body. I illustrate that the literature review does more than passively report on the findings of previous studies, rather it is a discursive practice where researchers play an active role in constructing the work of others and presenting themselves as an authority on the subject.

In the previous chapter I discussed the problem of how we represent knowledge. I am going to use the literature review as an exercise to highlight how knowledge is produced and represented. Gill (1998:24) suggests scientific writing conceals the fact that 'research is an active process, engaged in by embodied subjects, with emotions and theoretical and political commitments'. Aldridge (1993:54) notes how the practice of research writing represents texts as facts. She identifies the use of a number of 'rhetorical procedures' or conventions that mask the production of a text resulting in 'textually disembodied knowledge'. One example is the use of the third person in scientific genres- the removal of the I is a rhetorical accomplishment. That is, 'we are seen, rhetorically, to be doing science' (Aldridge, 1993:60; Latour and Woolgar, 1979). Squire (1990:40) highlights how the use of these devices masks the authority of the investigator who 'lurks behind every passive textual construction'. I have also numbered the different sections, which again is typical of the genre of scientific report writing, and is unique to this chapter. I am going to present an overview of the literature and then comment further on the literature review as a discursive practice.

1.1 Background

Cerebral palsy (CP) is an umbrella term used to describe a group of motor disabilities affecting movement and posture as a result of damage to the developing brain (Bax,

1964). Estimates of the numbers of children affected range from 1.2 and 2.36 per 1000 live births (Hagberg et al., 1996). Differences in estimates depend on the definition used and subsequent inclusion criteria. Since the 1960's survival rates for pre-term and low birth weight babies have increased and an increased prevalence in CP has been found in these groups. Low birth weight babies (i.e. <1000g or 2lbs) comprise 50% of CP children compared with 32% in earlier years (Pharoah and Cook, 1996). The authors also found an increased prevalence of CP amongst twins and multiple births. This association is of interest because of increases in infertility treatments.

There is also evidence to suggest that consanguinity (children born of related parents) is a risk factor for CP. Sinha et al., (1997) found a prevalence of 3.87-4.16 per 1000 births amongst the Asian community. In this study one half of families with a child with CP had at least one first cousin marriage, and a third of children had a relative with the same type of CP.

I step outside of the genre of the literature review at this point and use the autobiographical voice, which signals a discursive shift, to problematise medical discourses which construct a relationship between consanguinity (related marriage) and disability. I argue that this association forms part of a risk discourse that attributes health problems to cultural practices without attending to the material causes of illness and disability (Atkin, 1991). I argue that a focus on culture serves to 'other' cultural practices. Not only does this render the parents culpable, but masks the medical consequences of poverty such as poor maternal nutrition, which contributes to low birth weight and prematurity; both risk factors for disability (Scambler, 1997; Williams et al., 1996).

The example nicely illustrates how particular stories or versions, in this case a medical narrative which racialises the aetiology of disability, comes to be heard at the exclusion of other narratives about material deprivation. This is a theme I revisit throughout the thesis. I now revert back to the genre of scientific research writing.

Increases in survival rates of disabled children have been attributed to improvements in neonatal care as well as changes in attitudes towards the viability of children and

resuscitation practices (Hack and Fanaroff, 1999). The increase in the number of surviving children with cerebral palsy and other developmental disabilities has major implications for the planning and resourcing of educational, health and social services.

I again step out of the genre of the literature review to comment on the iatrogenic effects of medical interventions (Illich, 1975). For example, increasing levels of pre and post natal interventions have resulted in greater numbers of babies surviving with complex health needs which implicates science in the production of risk, another theme I revisit later in the thesis (Beck, 1992).

1.2 Growth

Many children with severe cerebral palsy, defined as those with four-limb involvement (spastic quadriplegia), are small and underweight relative to age standardised norms for reasons that are not fully understood. For example, 83% of children presenting for surgery are under the third centile for weight (Stringel, 1989). Research has shown that growth failure is often evident within the first six months of life (Reilly, 1992). A survey of adolescents and young adults with CP found that approximately one-fifth were emaciated, suggesting that these problems do not spontaneously resolve (Thomas et al., 1989).

1.3 Nutrition and physical health

The aetiology of poor growth is complex and multifactorial. However, there is a growing consensus that nutritional factors play an instrumental role (Stevenson et al., 1994). The term 'dysphagia' is used to describe any disorder of swallowing, including problems of sucking and chewing. A high proportion of children with neuro-developmental disabilities experience problems with feeding, making it difficult for them to achieve an adequate nutritional intake. Reilly et al., (1996) found that approximately 90% of pre-school children with CP have some degree of oro-motor problems. Eighty-percent of these children had been fed non-orally on at least one occasion.

There is also a high incidence of gastroesophageal reflux (the movement of the stomach contents into the oesophagus and sometimes the airway, resulting in projectile vomiting in extreme cases) in brain damaged children; rates as high as 70% (16/23) have been identified (Reyes et al., 1993). Symptoms suggestive of gastroesophageal reflux (GOR) include vomiting, regurgitation, abnormal posturing (for example, becoming tense, stiff and rigid), irritability and pain (Booth, 1992). Strictures (formation of scar tissue) can form as a result of reflux, which can damage the lining of the oesophagus leading to ulceration and bleeding and making it more difficult for food to pass down. This can also lead to iron-deficiency anaemia (Sullivan and Brueton, 1991).

The consequences of feeding difficulties are varied, weight loss being the most obvious. Calories may be lost due to frequent vomiting and regurgitation, because of spillage during feeding, or as a result of excessively slow eating. Respiratory complications may occur because food or liquid is aspirated into the respiratory tract during swallowing. Frequent chest infections leading to chronic lung damage is common (Heine et al., 1995). Further, given that 85% of brain growth takes place in the first 12 months of life, nutrition can affect the developing brain and, subsequently, a child's cognitive development (Skuse et al., 1994). Iron deficiency anaemia can cause poor performance on mental and motor tests amongst babies and children (Pollitt, 1994).

Poor nutrition may affect cognitive development in other ways: for example, by interfering with schooling, in terms of time lost through sickness, or by affecting a child's ability to concentrate through tiredness. The 'younger' appearance of undernourished children, due to growth retardation and delayed motor skills, may also be a contributing factor due to the lowered expectations of their carers (Pollitt, 1993).

1.4 Parental psychological well being

Severely disabled children often present with a range of complex health needs which make demands on family resources, both financially and emotionally. The burden of care associated with chronic illness is great and is usually the responsibility of the mother. Chronic stressors such as persistent child illness often resulting in frequent

admission to hospital, irritability, poor sleeping and a commitment of time needed to care for a sick child, including frequent attendance at clinic appointments, suggest that parental psychological well-being is also affected. There is a body of literature which attests to the high levels of psychological distress mother's may experience in relation to the care of a disabled child (Sloper and Turner, 1993; Beresford, 1993).

Children's feeding difficulties can also have an adverse affect on the family. Children may exhibit aversive behaviour when presented with food. For example, they may become stiff and tense, and may gag, retch, or choke while feeding. Vomiting may also follow meal times. Many parents talk of spending excessively long periods of time trying to feed their child and it is not unusual for some to spend as much as seven hours a day feeding (Johnson, 1985). It has been estimated that children with feeding difficulties can take up to 15 times longer to chew and swallow their food, and that mothers would have to spend in excess of waking hours in order to ensure their child received an adequate nutritional intake (Gisel and Patrick, 1988). Not surprisingly, mealtimes are often experienced as stressful for parents. One study indicated that many mothers were clinically depressed (Reilly and Skuse, 1992).

1.5 The management of children with feeding difficulties

Behavioural strategies attempt to introduce or re-introduce a child to oral feeding through a system of reinforcements. For children with swallowing difficulties, thickened feeds and a range of cups and utensils may be recommended. However, in children with severe neurological disability other interventions are usually considered. The placement of a nasogastric tube (tube put in the nose and passed down to the stomach) as a short-term measure, or the surgical placement of a gastrostomy tube in the child's stomach in the longer term, are usually prescribed.

Appropriate postural control, including specialised seating to maintain an upright sitting position during feeding, can help alleviate a child's reflux (Larnert and Ekberg, 1995). Although conventional drug therapy may be effective in up to 90% of patients with reflux (Sullivan and Brueton, 1991), a surgical fundoplication, also known as an antireflux procedure (ARP or Nissens), where the stomach is surgically tied to prevent a child vomiting, is usually recommended (Spitz, 1993).

1.6 Complications

The literature suggests that improvements in nutrition and catch-up growth can be achieved following tube feeding (Patrick et al., 1986; Brant et al., 1999). However, the placement of a gastrostomy is not without complications. A range of morbidity rates have been reported for gastrostomies ranging from 4-38% (studies quoted by Goretsky et al., 1996). For percutaneous endoscopic gastrostomies (PEGs), major complications can arise in 17.5% of cases, increasing to 22.5% for minor complications, such as infections at the gastrostomy site (Khattak et al., 1998). Variations in the rates of morbidity and mortality arise from differences in procedure and definition (Goretsky et al., 1996) and the health of the child. In some children, the placement of a gastrostomy can exacerbate or uncover hidden reflux necessitating a fundoplication (Ramachandran, 1996).

Puntis et al., (2000) found evidence of reflux following the placement of a PEG in 55% (15/27) of children (median length of follow up 2.6 years; range 0.4 to 4.9), but only two children required a fundoplication. The remainder were managed successfully with drug therapy. In a previous study, 14% (17/120) of children developed reflux, 10 of which required a fundoplication (Khattak et al., 1998). For this reason, the majority of centres in the UK do not perform both operations at the same time unless reflux is indicated. Alternatively, in the US both operations are routinely performed together (Seekri et al., 1991).

1.7 Economic costs and benefits associated with tube feeding

To date little work has been carried out on the costs associated with tube feeding and patient care in this group of children. Studies have tended to focus on the comparison of costs between different types of gastrostomy (Goretsky et al., 1996) rather than the broader picture. It has been suggested that gastrostomy-feeding technologies can be unpopular amongst parents, namely in the US and Australia, because of the financial costs incurred as a result of the new technology⁶. Unlike the UK, where the NHS meets

⁶ Personal communication Professor S. Reilly, Faculty of Health Sciences, La Trobe University.

the costs of gastrostomy tubes and related equipment, the cost of equipment in these countries is born by the individual families. The cost effectiveness of treatments is of increasing concern to the NHS.

Why evaluate now: Benefits the proposed investigation will bring to the NHS?

The study was designed to provide much needed evidence regarding the medical and psychological costs and benefits of gastrostomy feeding interventions in children with severe disabilities. The concept of gastrostomy however is not a new one. The literature indicates that the first successful gastrostomy was performed as early as 1876. However, Gauderer only carried out the first PEG as recently as 1980 (Khattak et al., 1998). Palfrey (1994) found a 36% increase in the use of gastrostomy between 1987 and 1990 in one study in Massachusetts. The use of gastrostomy feeding in children with cerebral palsy (CP) has also increased in the last 10 years (Heine et al., 1995). However, despite the increase in use, there has been no systematic study of the medical and psychological costs and benefits of the procedure. The evidence that is available is either of an anecdotal nature, or comes from data from retrospective studies. A need for a systematic study of contraindications is therefore warranted.

In particular, very little work has been carried out on parental perceptions of gastrostomy tube feeding (Thorne et al., 1997). Although there is evidence to suggest that parents report satisfaction with the procedure (McGrath, 1992; Tawfik; 1997), it can sometimes generate opposition (Thorne et al., 1996). Gastrostomy feeding has become a contentious issue for both parents and health professionals (Reilly, 2000). The increasing adoption of gastrostomy as a management strategy for children with severe neurological disability therefore presents a number of ethical dilemmas for both families and clinicians. The study was designed to shed greater light on parental attitudes and acceptability.

Conclusion

The research narrative begins with an overview of relevant research and situates the review within the scientific literature. Gill (1998:25) argues that in reviewing the literature researchers are constructing other's research while establishing themselves as an authority 'having a wider and more sophisticated vision, a greater knowledge of the field' – in short, an accomplishment of self. The narrative structure is one of a need for systematic evidence of the costs and benefits of the procedure by identifying the gaps in our knowledge that the proposed research study promises to fill, bringing significant improvements. Kitzinger (1990:69) suggests that in exposing the deficiencies of other studies, researchers are offering a 'curtain-raiser for their own superior 'truly scientific research'.

Systematic evidence is equated with methods within discourses of evidence. The guarantor of rigour is the controlled experimental trial and use of standard tools and objective tests to measure outcomes (this is explored further in the next chapter). Burman and Parker (1993:2) describe the 'experimental discourse' as: 'a set of statements, terms, metaphors and turns of phrase which include 'subjects', 'control conditions', 'variables' and 'results'. The economic evaluation reflects a discourse of 'economic rationalism' (Cheek, 2000), a fairly pervasive discourse in the current NHS.

Research texts are also subjected to a regulation of temporal ordering (Aldridge, 1993:62), where the literature review is always presented at the beginning of the research report or thesis as part of the first stage of the research process, constructed as logical and sequential. However we all know that over a four year period the review becomes outdated and has to be constantly revised in the light of new work. It is conceivable that a second literature review could be inserted at the end of our reports. However the fact that many researchers review the literature at the end of the research study, rather than at the beginning, is rarely reported.

A prevalent medical discourse in feeding and disabled children revolves around poor nutrition and malnourishment, with implications for children's growth and cognitive

development and the psychological well being of their parents prompting the perception of a need for an intervention. Children and their families therefore are constructed as objects of a feeding discourse (Dayle and McIntyre, 2003). Metaphors of dysfunction (i.e. faulty machines) are used to represent children and their families. The discourse of 'psychological well being' constructs children as a 'burden' to their mothers in terms of the demands of care and forms part of the rationale for a gastrostomy tube. A discourse of cause and effect is used to construct a relationship between the child's feeding difficulties and maternal depression. Medical discourse constructs the solution to the problem as one of a medical intervention in the form of a gastrostomy and/or antireflux procedure.

Nightingale (1999:172), in a deconstruction of medical texts describing William's syndrome, demonstrates how such texts represent a classic medical model of the disabled person. Applying his framework to the literature review presented here reveals a construction of disabled children and their families in terms of a set of symptoms ranging from the bio-genetic (for example, the aetiology of cerebral palsy), physiological (reflux and aspiration), psychological (impaired cognitive development), social (stress and family functioning, children's schooling) and, increasingly, the economic (costs to the NHS). In defining the problem and the solution, medical discourse subordinates alternative constructions of the child, feeding and parenting. However, disability activists have challenged medical representations of disability in terms of impairment (Oliver, 1990) suggesting alternative constructions of disability are available but muted within medical discourses. I present competing constructions of feeding disabled children to those suggested by medical discourses in the remainder of this thesis.

My exposé of the discursive framing of the literature review is not designed to privilege alternative ways of writing or presenting knowledge, as no writing is free of rhetorical turns (Aldridge, 1993). The use of confessional accounts in research for example, has been criticised for seeming to dilute the authorial voice. Gill (1998;1995) criticises the way 'new literary forms' are used as a reflexive tool which seeks to challenge orthodox ways of writing. Rhetorical devices, for example presenting work as a dialogue with self or others, she argues, is akin to a fake 'multi-vocality' or 'pluralism' when in fact

all the voices are those of the authors'. The fact that the voices are not 'owned', she suggests, rather than decentering the author, raises issues about accountability (1995:181). I return to issues of how we represent and communicate our research in the final chapter.

In the next chapter I reveal how professional practices in the management of children's feeding subvert discourses of science and evidence. I argue that clinical practice, underpinned by a discourse of objectivity, rests on bodies of knowledge that are contestable, contradictory and shifting.

4. Towards evidence based practice: The medicalisation of feeding

Introduction

The NHS Research and Development programme launched a strategy of evidence based medicine (EBM) in 1991. The aim was to 'secure a knowledge-based health service in which clinical, managerial and policy decisions were based on sound and pertinent information' (Walshe and Ham, 1997:22). Subsequently a whole infrastructure was established to support the initiative in the form of national centres, publications and guidelines designed to make clinical practice evidence based⁷. The philosophy, essentially positivist, and underpinned by an Enlightenment discourse, is not new but encourages clinicians to make decisions about treatments based on clinical expertise and the best available research evidence (Sackett et al., 1996). Evidence is ordered in accordance with a hierarchy of methods with randomised controlled trials (RCTs) privileged as the 'gold standard'. EBM seeks to render medicine more objective and therefore scientific. The development of an evidence culture is also seen as a way of enhancing the quality of care by making professional practice more clinically effective (Summerton, 1997).

In this chapter I explore whether clinicians' practice can be said to be evidence based and the consequences for patient care and multi-disciplinary working. Drawing on Fox's (1994;1993) study of surgeons and anaesthetists, I identify a number of rival perspectives informing the clinical management of children with feeding difficulties. I argue that surgeons construct the surgical patient in radically different ways to those clinicians whose practice is organised by a neurological discourse, including speech and language therapists. I examine how the different discursive frameworks that organise clinical practice result in rival discourses that have consequences for patient

⁷ The UK Cochrane Centre for example was established as part of an international network with the aim of providing systematic reviews of research into the effects of health care. A database containing these reviews is available and clinicians are encouraged to use the database to inform their decisions about treatments.

care. In order to do this I draw on a number of 'contexts' informed by observations of clinical consultations, patient records, research and clinical meetings, as well as extracts from interviews with parents. Each section in the chapter addresses an aspect of children's clinical management and/or the interface with research practice. Each section is prefaced with a justification for the reason why I chose that particular aspect of patient care as a 'context' for further analysis.

Tests and Investigations

A number of tests and investigations are used in the clinical management of children with feeding difficulties. These range from blood tests to determine a child's health and nutritional status, to x-rays which examine respiratory status, reflux and aspiration, for example, chest x-rays, videofluoroscopy, barium swallow and 24-hour ph monitoring. I describe the different uses and interpretations of these investigations with the aim of highlighting a number of contradictions within scientific discourse in relation to the role of laboratory medicine in informing clinical and research practice. I will argue that the use and interpretation of technology 'supplies a discourse' by which different professionals define themselves (Fox, 1994:4). In highlighting the contradictions inherent in the medical sciences I want to problematise notions of objectivity. I also show that research activities, with their emphasis on the production of objective evidence are in danger of compromising the relationship between clinician and patient. Moreover, they may be misguided in their attempts to inform clinical practice by failing to acknowledge differing perceptions of risk, and the role of hierarchy and power in institutions in informing clinical judgements.

In the next section I discuss the role of blood tests in children's care. This raised a number of ethical issues in relation to my positioning within institutionalised discourses (although I revisit ethical issues in more detail in the next chapter). In the second part I discuss a number of x-ray investigations, which often produced results contrary to parental experiences and were interpreted in different ways by clinicians despite their status as the 'gold standard'.

In the third section, by way of making sense of variations in clinical practice, I discuss the concept of explanatory models (Kleinman, 1980) or discursive frameworks which clinicians draw on to inform their practices which are also underpinned by the perception of risk. I argue that the intersections of institutional and disciplinary resources compromise the independence /objectivity of evidence based practice (EBP) with consequences for patient care; a theme which I take up in the concluding chapter on what constitutes good care.

Blood tests

The role of blood tests in the clinical management of children and research was identified as a 'context' for further analysis for the following reasons:

- blood tests were constructed as 'objective' measures in the research proposal and were therefore privileged as a superior measure of a child's health and nutritional status;
- there was a tension surrounding the status of the tests and whether they formed part of the child's routine clinical management or were being used specifically for research purposes. The distinction was important as it had implications for gaining parental consent and research practice;
- there were specific issues around gaining parental and professional consent. As I played an instrumental role in obtaining consent it warrants further reflection;
- the blood tests provide an example of the blurring of boundaries between research and clinical practice which raises a number of ethical concerns;
- the interface between the clinical services and research raised issues about informed consent in terms of what was communicated to families and their understanding of the informed consent procedure; and
- there was no system in place to deal with abnormal test results as they were collected for research purposes.

A number of health and nutritional indices were used as outcome measures including blood tests pre and post gastrostomy placement⁸. The issue of blood samples to investigate a child's health and nutritional status for the purposes of research remained contentious, not only for me, as I had to obtain parental consent and ensure the samples were taken, but for some of the clinicians. Initially, there was some discussion within the steering group about whether the blood tests could be classified as a routine clinical procedure or whether they should be viewed purely in terms of investigations for research purposes. If there was agreement that the blood tests could be justified as a routine procedure, they would not require parental consent and could be taken when the families attended their initial appointment in the outpatient clinic. This was essential if we were to obtain two measures preoperatively, necessary in order to establish a baseline with which to compare outcomes post operatively, ensuring a sufficient time lapse between the two measurements. When the matter was discussed with the steering group, it became apparent that some clinicians, for example the neurologists, dieticians and those working within the speciality of metabolic medicine, would carry out the majority of the blood tests detailed in the research protocol as a matter of course in the management of their patients. However, the surgeons did not routinely use them, and some adopted the position that as blood tests were an invasive procedure, they could not be justified for research despite having ethical approval and parental consent. The non-surgical colleagues were surprised that a child could undergo surgery without prior testing⁹, their clinical practice being much more reliant on these types of investigations. This example illustrates the professional differences in disciplinary approaches to the monitoring and investigation of children within the medical and surgical fraternities.

Further, there was some debate about how much blood, in terms of volume, was considered 'a lot' in relation to a child's age. Hospital guidelines may advise more than is strictly necessary in order to ensure a sufficient quantity for analysis. I had been advised that eight millilitres would cover all the tests that were needed, but when a nurse commented that this was a large quantity for young babies I requested further

⁸ These were Copper, Zinc, Total protein, Immunoglobulins, Ferritin, Iron, Protein, Full Blood Count.

⁹ Gastrostomies placed endoscopically, eg. the PEG, do not usually require blood tests prior to surgery.

clarification from the steering group. Again there was a difference of opinion between the various sub-specialisms in the group about what volume would be considered 'too much' for a child of a given age. The surgeon was uneasy about the proposed volume of blood, whereas other clinicians were less concerned as they were used to taking larger quantities (up to four times more in some instances) in the management of patients. Further there is very little in the literature to guide these procedures (Clayton et al., 1980)

Subsequently I sought an agreement with the different laboratories responsible for analysing the blood tests that we would submit samples containing the absolute minimum required for any given analysis. The picture was further complicated when the head of one laboratory disputed the use value of some of the proposed tests suggesting alternatives that he felt would be more valid in the investigation of a child's nutritional status¹⁰.

Further, at a paediatric dysphagia meeting involving local paediatricians, one doctor commented that although blood tests were used to monitor a child's nutritional status, rarely did the results indicate that the child was nutritionally deficient, which is surprising given the concerns about poor nourishment in this group of children. Similarly parents also questioned whether the results of the blood tests reflected the health status of their children. One family, for example, felt there were significant, visible changes in their child's skin, hair and nails following gastrostomy insertion. Again pre-operative blood tests had not indicated a deficiency of any kind - a fact disputed by the parents.

Gaining consent for biomedical tests

One of the major concerns parents expressed about the research was whether their child's participation would involve additional tests and investigations. As co-ordinator,

¹⁰ for example, calcium, magnesium and urea

I was responsible for recruiting children and their families into the study, explaining the reasons for the research and any potential risks. This is also an ethics committee requirement. However, although I usually explained that there was no direct benefit to children who took part in the study, this was actually quite difficult to communicate in practice, for if there were no benefit why would families consent to the additional tests? Further, what we say (overt communication) may be at odds with other things we are communicating (covert communication). It could be argued that the terminology I used, 'special tests' and 'closer monitoring of children', was suggestive of a benefit. As such, I invited parents to invest in the rationale of the research and the logic of biomedical testing and, perhaps, allowed families to mislead themselves about the potential benefits of taking part in the research in order to gain their consent and participation. Moreover, as blood tests form part of routine hospital procedures, parents presumably accept the tests play a role in patient care.

The reasons parents gave for refusal were that they did not want their child subjected to any additional unnecessary procedures. In particular, parents spoke of the difficulties involved in obtaining blood samples and the subsequent distress to the child. I usually acknowledged this when explaining the research to families and told them the pre-operative bloods would be taken under anaesthetic while the child was having surgery. Most parents agreed to this aspect but expressed a concern about how the 'bloods' would be taken at follow up. I usually asked them to consider deferring consent on the post operative 'bloods' till their follow up appointment. Procedural consent may be empowering (Munhall, 1988) but it also provides the researcher with another opportunity to re-negotiate specific aspects of the project and it may be more difficult for parents to refuse consent further down the line when they have already invested in the research.

This example illustrates what Scambler and Britten (2001:53) drawing on the work of Habermas (1984) refer to as 'distorted' communication'. That is, where there is a hidden agenda (e.g. getting parents to comply with the blood tests) which is not communicated to the participant and as such involves a deception. Distorted communication, or misunderstandings, happen as a result of 'confusions between actions oriented to understandings and actions oriented to success' (Scambler and

Britten 2001:53) and are characterised by 'asymmetrical power relations' (Wodak, 1996:30). Wodak suggests that: 'Normative power exists within an organisation when communicative action is distorted through the imposition of interests particular to a certain group' (1996:30). Conversely, actions oriented towards understandings are seen as ideal speech situations and are characterised by an absence of power relationships.

Skeggs (1994) suggests women's willingness to participate in research is a reflection of their powerlessness. However, some women were able to refuse, including one parent who was a medical professional. Sometimes women deferred the decision in order to consult with their partners. Some women, although unable to register their objection directly, later telephoned to say they did not want their child to have the tests. One mother, who did not consent to participate in any aspect of the research, told me her child's hand was 'like a pin-cushion' - a veiled protest perhaps about the perceived over-investigation of her child and 'treatment fatigue'.

The bartering around consent exemplifies a trading of power between researcher and researched as agreement about which aspects of the study parents are willing to participate in are negotiated. Such a process is rarely described in research reports when response rates are presented as a percentage obscuring the context of research practice and wider power relations that inform the consent procedure. This resonates with Oakley's (1981) description of research as 'hygienic'.

Whereas some clinicians within the steering group were able to appreciate parental concerns about participating in the study, others expressed the view that the move towards patients' rights had threatened the professionals' 'rights' to do research, and that families attending teaching and research hospitals should expect to take part in research. A conflict between a patient's right not to participate in research and the pressure on clinicians to demonstrate that their practice is evidence based is apparent here, echoing the rhetoric of no rights [to healthcare] without responsibilities perhaps. This is particularly stark in teaching and research institutions where research and funding are so closely tied. For if families refuse to take part in research, this has implications not only for institutional funding, but clinical practice and its evidence base.

The conflation of treatment with research was particularly marked over the issue of blood samples at the six month follow up. There was one family with whom I had established a research relationship, through home visits and telephone calls. They were very willing to participate in all aspects of the research. I arranged for the blood tests to be carried out, which took a very long time partly because it was difficult to access the child's veins, and partly due to the inexperience of the houseman. Two events followed: the first, was that one blood test did read as abnormal. The second was a concern expressed by the nursing staff about the amount of time needed to take the sample, whether the tests had caused the child distress, and was this justified for the purposes of research. Perhaps of greater concern was the issue of the impact of the research on the clinical service, as by asking a nurse to assist in taking the blood samples, she was temporarily taken away from the service and other patients.

As the tests were carried out as part of a research study and did not strictly form part of the children's routine care (although this was always contested), there was no mechanism in place to deal with any abnormal results. Further, none of the staff on the research team were 'clinically' responsible for the children and it was not appropriate for me to discuss the results with the parents. Given the issue of bloods was a contentious one, I felt some responsibility for ensuring a mechanism was in place to act upon any abnormal test results. The challenge was to find someone actively involved in the management of the children's care who was sympathetic to the aims of the research and who felt able to interpret and act on the tests.

In the case of this particular child I was able to identify a clinician involved in the child's management and passed on the results. I then wrote to the parents, as promised, informing them that the results had been referred to the clinician who would be able to act upon them. I was deliberately vague about the outcome of the tests so as not to alarm them, but they were obviously concerned and contacted the clinician. However, the clinician had some difficulty in interpreting the results given that the child's nutritional intake was adequate according to a computerised calculation. She was therefore unable to understand why the test had read as abnormal. In all probability, the next stage would have been to repeat the test.

I was then left to reflect on whether the logic of testing was flawed. However, as co-ordinator of the project I had to keep with the official line that the tests were necessary in order to establish a baseline with which to compare outcomes. Perhaps of a more serious nature was the responsibility I felt toward the family. Although the parents had not spoken to me directly about the matter, I was very aware of the anxiety an abnormal test result can create through my previous experience of research. Having played an instrumental role in persuading the family to invest in the logic of testing in order to gain their consent, it would be difficult to downplay the role and value of the tests. Now there was a question mark over the role of the tests in terms of the child's clinical management.

The second event that followed was the concern expressed by the nursing staff that blood tests for research purposes were taking personnel away from the clinical service, which added to the waiting times. Further, the nurse who assisted the houseman was unhappy at having to assist a relatively inexperienced doctor in taking the blood samples, a task in which she exercised greater competency. Subsequently, my strategy was to reassure the nurses that there was a clinical benefit to the tests.

I then went back to the steering group and asked for a procedure to deal with any abnormal test results to ensure that children received appropriate follow-up and that the parents' willingness to help had not been exploited. Although initially it was suggested there was no obligation to disclose results to parents because the blood tests were for research purposes, the surgical representative agreed to pass on any abnormal results to his surgical colleagues for them to action.

Although ethical approval had been sought and given with respect to the blood tests, ethics committees do not cater for the unforeseen/inadvertent distress this kind of research can potentially create. As discussed previously, ethics committees are based on the biomedical model of research underpinned by a morality which states that as long as the research is adding to knowledge, and therefore doing good, it is alright to do a little harm.

Coincidentally, some weeks later, the hospital held a clinical effectiveness meeting which was organised as part of a series of meetings designed to facilitate the sharing of clinical experience. The theme of the session was 'taking bloods from small children'. The aim was to train clinicians in evidence based practice by formulating appropriate questions and searching for evidence to provide the answers. It was asked which of two procedures, venepuncture¹¹ or heel lance¹², commonly used to take bloods was the most clinically effective? The audience was guided through an on-line search of the literature and was surprised, given the frequency with which blood tests are carried out, to find only two systematic reviews on the Cochrane database, and these were only partially relevant, to the question posed (Shah and Ohlsson 2003). The evidence pointed to venepuncture as the favoured method for blood sampling, although intuitively, many clinicians felt heel prick should be used.

Interestingly, (in relation to questions of parental consent and claims to knowledge) one of the mothers participating in the gastrostomy study, who was used to taking bloods from her child herself on a regular basis to monitor diabetes, requested that her child's blood samples be taken by 'finger-prick'. The nurse in the outpatient clinic was uncomfortable with this method preferring to use venepuncture. However, the mother was adamant the only way she would consent to the blood tests was if her preferred method was used; the nurse reluctantly agreed. Here is an example of the way a parent 'seizes power in discourse' such that despite her institutional position as parent/patient, she achieves power in that instant demonstrating that parents are rarely, completely powerless within institutionalised discourses (Walkerdine, 1990:5).

One surgical colleague in particular refused permission for blood samples to be taken from his patients, arguing that the tests were invasive and not clinically indicated. Here an ethical discourse was invoked to protect his patients and his professional autonomy from the research gaze. Again the power of the gatekeepers in influencing research activities is evident. Claims that research and, subsequently, institutional funding, are

¹¹ where blood is taken from a vein in the child's arm using a syringe

¹² blood is taken from the child's heel

under threat from non-compliant clinicians are however, rarely voiced (Prescott et al., 1999).

These two examples serve to illustrate how both clinicians and parents are able to wield power and frustrate the research process; in the mother's case, because she had an expertise normally assumed by medical people, that of 'taking bloods'.

X-rays: videofluoroscopy, barium swallows, chest x-rays and pH studies

I have argued that the taking of blood samples in research and clinical care is a discursive practice. I have also identified a number of other investigations as a 'context' for analysis for the following reasons:

- they were used in the clinical management of children with feeding difficulties to investigate reflux and aspiration;
- the tests were referred to as the 'gold standard' and therefore privileged as the best objective evidence;
- the test results were sometimes contradictory or inconclusive;
- parents did not always agree that the results had adequately reflected their child's feeding or health status; and
- different groups of clinicians attached different values to the role and interpretation of the tests in relation to treatments.

Barium swallow and videofluoroscopy

A barium swallow (which is an x-ray investigation) is carried out to ascertain whether a child has reflux. This is sometimes done in combination with a videofluoroscopy or swallow assessment (which is also an x-ray investigation). The tests are usually carried out while a child eats barium or food with barium. A videofluoroscopy is used to assess the safety of a child's swallow and the risk of aspiration (i.e. where food is transported into the airway). A barium swallow can detect whether there is an anatomical reason for a child refluxing, such as a hernia. The focus and purpose of each test therefore is

slightly different. The value attached to these investigations also differed as a function of clinical specialism, with surgeons more likely to request a barium swallow and neurologists and speech and language therapists a videofluoroscopy in addition.

Parents also attached varying degrees of significance to the test results. The fact that aspiration can be silent (i.e. no outward or visible signs of respiratory distress such as coughing or choking or chest infections/pneumonia) can be a conceptual barrier for doctors and families alike. For example, a local speech and language therapist wrote a detailed report advising one parent (a health professional) against orally feeding her child. The therapist justified her decision based on the following criteria: an absence of spontaneous sucking; aspiration due to an ineffective cough reflex, and hence an inability to protect her airway; and reflux which had caused the child to be aversive to oral feeding. However, at the six-month follow-up meeting the mother said the child was eating three meals a day, which, she asserted, proved she did not have a feeding difficulty. Further, as the child had not experienced any chest infections, the mother remained unconvinced that aspiration presented a risk to her child's health. The mother continued to feed orally and turned down the offer of another videofluoroscopy to assess the child's feeding ability. Here she takes up the subject position of 'mother knows best' and resists the medical definition of her child's problem.

In another example a mother had been advised by the local speech therapist against oral feeding because the child aspirated as a result of an 'incoordinate swallow'. The mother raised this with the surgeon in the outpatient clinic and asked about the possibility of repeating the videofluoroscopy. The consultant told her it was not necessary and argued that if the child's aspiration was severe, she would aspirate on her own saliva. Here the surgeon is drawing on a normalising discourse (i.e. aspiration is a natural state for her and therefore cannot be harmful). In the face of conflicting advice about her child's feeding management, the mother deferred to the surgeon's reasoning which, in this case, coincided with her own. A complex range of factors may be at play in influencing the mother's decision to accept the surgeon's version of events, including his professional seniority as a (male) surgeon, institutional factors (the advice comes from a centre of excellence) and advice which is compatible with the mother's world view,

plus the weight of evaluation of her as a 'responsible' mother receiving a health service.

The mysticism of 'silent' aspiration - only visible through an x-ray - may be one reason for disagreements about the potential health risks to children. Additionally the evidence relating aspiration and pulmonary disease is sparse (Groher, 1994). For example, some children appear able to protect their 'airways' whereas others cannot for reasons that are not clearly understood. The view expressed by the surgeons that aspiration detected by videofluoroscopy represented a 'radiological' (i.e. technical) rather than a 'clinical' diagnosis, highlights contested knowledges between different clinicians specialising in children's feeding and suggests that the 'gold standards' provided by the formal investigations are subordinated to clinical judgement.

Additionally, it is clear that different clinicians use other decision criteria in addition to the information provided by the laboratory tests. In one example a child was referred to a surgeon for an assessment for a gastrostomy. The barium swallow indicated aspiration and the child had a history of recurrent chest infections including frequent hospitalisations. The mother reported that feeding was difficult and 'slow'. The surgeon felt that as the child appeared well nourished (contrary to information provided by the growth charts), and did not exhibit symptoms of coughing or choking when drinking, that the mother should persevere given gastrostomy surgery was not without risks. The mother appeared confused and reiterated her concerns about the risks of aspiration. The consultant advised her to persist with oral feeding and to 'thicken' the child's feeds. The mother then asked for advice on how to do this to which the consultant replied (somewhat irritably), 'with cereal'. At this point it is clear that the consultant is not going to refer the child for surgery as the mother has not 'earned' her 'right' to a gastrostomy for her child. The mother may have benefited from further advice on feeding management but this was not offered. The naturalisation of feeding as women's work means women are expected to get on with feeding and are often denied the help they seek. The surgeon subsequently changed tack and suggested that if the mother continued to have problems she should return and they would reconsider the decision. The surgeon appeared to be delaying, rather than refusing, the operation.

Parents may also find the different tests confusing or feel they have not adequately reflected real life circumstances, for example feeding a child under laboratory conditions compared to feeding a child at home. Subsequently parents expressed a concern that the tests may have misrepresented their child's feeding skills especially when different test results were contradictory. In John's case, although aspiration was detected by the videofluoroscopy, the chest x-rays did not indicate that aspiration was causing him harm:

We looked at the results of that video again and yeah, John was aspirating, but it was to us a totally false set of circumstances because of the apparatus, he's got to sit in a completely different position to how he normally sits. He, he was, we were going through some speech and language therapy, we use the (name of alternative therapy centre) a lot, yeah, don't know if you're familiar with that? Yeah, we've been getting on well with feeding with using sort of cups instead of bottles and what-have-you, you know. So we really felt we'd come on, and the video didn't really represent too much. Every time we've had a look at the chest x-ray it's been perfectly clear. [John's father, 1/1]

That tests and investigations often indicated events contrary to parental (and clinical) experience and beliefs suggests there are different ways of reading or interpreting the body premised on different kinds of evidence (Wynne, 1998). In fact the ability of chest x-rays to detect damage as a result of aspiration is disputed on the grounds that they only provide a 'snapshot' of the child's health at any given point in time.

Women's accounts did incorporate medical knowledge (perhaps unsurprisingly), suggesting not all expert knowledge is rejected. Moreover, some parents, while rejecting the recommendation of a gastrostomy, agreed to the use of a range of other feeding technologies such as thickeners in feeds, specialised feeding utensils, and nasogastric tubes. Yet in accepting the need for particular feeding interventions, they were incorporating a medical model of their child's problems. Kay's mother for example discounted the diagnosis of aspiration on the grounds that Kay had not experienced any chest infections, did not show evidence of distress when eating and, as she had gained weight, the mother rationalised that the food must have gone into the right place:

I have reduced her food at the moment because there was some concern that some of it was blocking her airway and sometimes going into her lungs but she was on a lot more than she's on at the moment, and they say that some of it might be blocking her airways. But from what I've seen, of when she was on more food, she's putting on loads of weight, so I can't see how it went into her lungs without affecting her or giving her chest infection. All I saw was that she's putting on weight so it must have gone to the right place. She never coughs or splutters with us when we give her food so I assume it must be going to her stomach. [Kay's mother, 1/2]

In attempting to understand the different perspectives of doctors and patients social scientists have posited the dualism of lay and expert knowledges which inform these perspectives. This dualism suggests that doctor's knowledge is grounded in the individualised disease model whereas lay people's knowledge is derived from the everyday experience of illness rooted in the context of the life world (Williams and Popay, 2001). However, despite Kay's mother's rationalisations, she accepted the doctors' advice to use the NG tube and cut down on oral feeding. She therefore takes up the subject position of 'responsible' (i.e. compliant) mother within professional discourse.

The power of medicine with its use of diagnostic technology, the training, expertise and status of physicians and their perceived ability to cure illness and save lives are compelling influences on parental decision making. Nettleton (1991:101) argues that it is through the 'vocabulary of the experts' that patients 'interpret their own experiences and construct themselves'. Expert knowledge is incorporated to the extent that it can be 'reinterpreted in terms of the experience of everyday life' (Williams and Popay, 1994:122). That is, a mother will want to relate this knowledge in terms of the narrative and biography of her own life. The influence of social class, gender, ethnicity and previous experience with the medical profession may also determine to what extent parents accept the medical diagnosis and treatment.

The dualism between lay and expert knowledge is problematic however because of the medical colonisation, and the cultural dissemination, of knowledge which allows for the transformation of expert/lay knowledges (Walker, 1988). This is aptly reflected in the 'psy' professions (Rose, 1985), which illustrate how disciplinary practices not only socialise professionals, but increasingly, lay people. This was very apparent in my role

as advocate and information provider (discussed in the next chapter) and, when, after having left my job, I received an e-mail from a mother in Ireland asking for information about gastrostomies so that she could make an 'informed choice', thereby constructing me as an expert. Her use of the term 'informed choice' is evidence of the assimilation of a professional discourse which, again, undermines the lay/expert binary.

Although some parents accepted the test results, they did not necessarily accept the recommendation to stop feeding orally. For example, one child was referred by her school because the school carers had experienced problems feeding her and reported two incidents, involving choking, which raised concerns about the safety of oral feeding. Subsequently, against the wishes of the family, the carers refused to feed the child orally. Neither the nursing staff at the residential unit where the girl boarded, nor members of the family had experienced problems with feeding. The mother suggested the choking incidents had arisen because of the carer's inexperience with feeding disabled children - a case of 'new beginners'. Although a videofluoroscopy indicated that the child was aspirating the mother expressed her reluctance to move to tube feeding given the child's love of food ('it's her passion'). The consultant was happy to respect the mother's wishes not to proceed with a gastrostomy providing she was prepared to accept the risks. Evidence based practice was therefore subordinated to risk; the responsibility for which was passed back to the parent. The mother's willingness to accept risk was recorded in the child's hospital notes, a safeguard in the event of litigation perhaps. Here the right of the child to a safe and adequate form of nutrition was confounded with notions of risk and who was responsible for that risk. I return to the theme of risk later in the chapter.

24-hour pH monitoring

Twenty-four hour ambulatory pH monitoring is considered to be the 'gold standard' for diagnosing gastroesophageal reflux. That is, a pH probe is inserted into the oesophagus and the level of acidity is measured over a 24-hour period during which a patient's routine daily activities are simulated. A pH below 4 for greater than 5% of the time is considered to be a positive result indicating reflux. Helman, (1984:88) notes the increasing use of numerical definitions of health and disease in modern medicine.

The reliability of pH monitoring in identifying reflux has been questioned by a number of studies (e.g. Hampton 1992; Mitchell 2001) and my own observations suggested that some groups of clinicians disregarded the results of the tests. For example, two specialists, a neurologist and an orthopaedic surgeon, independently referred an older child for a surgical consultation for a gastrostomy tube. The former made the referral because of concerns about poor growth, aspiration and reflux, which had been described as severe and confirmed by the laboratory tests. The orthopaedic surgeon made the referral because the child needed a hip operation but had to increase his weight before the operation could be carried out.

The mother was unclear about the best way forward since, although she accepted the child needed orthopaedic surgery, she disputed that there were problems with the child's feeding and was generally opposed to the idea of a gastrostomy given the child 'loved his food'. The surgeon did not see any reason to go ahead with the gastrostomy given the child did not vomit or choke, enjoyed his food and had only experienced one episode of respiratory infection in the previous 18 months. Moreover he was not prepared to proceed with surgery on the grounds that the child needed the weight-gain for another operation. Here the balance of professional control over the patient shifts from the consultants who made the referral, to the surgeon. However, the surgeon discursively shifts the responsibility for patient care, and hence risk, back to the referring doctors through his inaction. The surgeon's definition of who needs surgery resides in his clinical judgement and not the results of the laboratory tests.

The neurologist who made the referral was extremely concerned about the child and argued that as the child had no cough reflex, he was unable to cough and would not demonstrate any visible signs of distress - a case of silent aspiration. In fact the distress to the child occurred some 10-15 minutes after the swallow study had been conducted (in real time as opposed to laboratory time). Some three months later, the child suffered a dramatic loss of weight, the chest x-ray did show changes congruent with aspiration and the child was re-referred for surgery. At this point the parents demanded to know why no one had acted sooner and requested immediate surgery. The inscription of the patient within a neurological discourse conflicted with the surgical definition of the patient which, in this example, resulted in adverse effects for the patient.

Discursive frameworks

The examples I have discussed throughout this chapter would appear to suggest a lack of consensus about the management of children with feeding difficulties and the role of tests and investigations in clinical decision making. Similarly, families often queried the meaning of test results suggesting a lack of transparency about their role and interpretation. However, the apparent anomalies can be understood in terms of the different discursive frameworks clinicians employ which frame diseases and patients in unique ways (Helman, 1984). Latour and Woolgar (1979) note the way scientists use frameworks to impose order and filter out the 'noise' (disorder) in order to arrive at a rational explanation out of a number of competing explanations.

Surgical practice is organised by an oppositional discourse: 'between surgery as a healing process and surgery as a (necessarily) injurious procedure' (Fox, 1993:37). Surgeons' perceptions of risk therefore take this into account. The surgeons' questioning, for example, would lead them to assess the problem in very different terms to the neurologists. Asking whether a child eats is a different question to ascertaining whether it is 'safe' for a child to eat. Surgeons may not ask about the safety of oral feeding because they have to evaluate the risk of harm of aspiration to the child against the risks involved in surgically inserting a gastrostomy. Their frameworks are also organised by a discourse of normalisation (i.e. to maintain oral feeding). For the surgeon, aspiration may not present a high enough risk to warrant a surgical intervention. Hence, the neurological discourse of aspiration is marginalised within a surgical risk discourse.

Conversely, the speech and language therapists' practice is organised by a neurological discourse. As such, they are more likely to caution against oral feeding on safety grounds. As therapists have a legal duty of care towards their patients, it could be argued that it is also the fear of litigation that underpins this advice despite the fact it is very rare for a therapist to be sued for negligence (Horner, 1999).

The surgeon's attempts to ascertain whether a child has reflux by asking if a child vomits is again a different approach to that used by a neurologist, who is more likely to

ask about evidence of pain and irritability as a sign of reflux, given a child can have reflux but may not vomit. On occasion, when the test results contradicted parental experience, the surgeons would defer to the parents' accounts. This suggests a favouring of treating overt symptoms as opposed to 'sub-clinical' findings. The surgeon's decision making is operating within 'real' as opposed to 'laboratory' time (that is, rooted in the life world of the family). For surgeons the reflux has to manifest itself in the form of vomiting before they are prepared to take the risk of performing surgery on a child. An investigation which identifies a cause and effect approach to treatment such as a barium swallow, which may identify an anatomical reason for the child's vomiting, is of greater insight to a surgeon operating within a 'can do/can fix it' discourse. Diseases with an underlying neurological base (e.g. pharyngeal aspiration) are less amenable to a 'fix it' approach and therefore fall outside the surgeon's conceptual model.

Not only is clinical decision making influenced by the different discursive frameworks specialists use, but by a hierarchy of power and deference (which is also gendered) based on the professional credentials of clinicians. In the medical hierarchy, the expertise of speech and language therapists (a 'profession allied to medicine') and paediatric neurologists, both predominantly female professions, are subordinate to that of the (male) surgeons. Even within the sub-specialism of surgery, orthopaedics is considered to be 'low' status. The surgical consultant therefore is unlikely to defer to those positioned lower down the hierarchy. Further, the downplaying of the expertise of speech and language therapists on the grounds that their practice is not evidence based has been used as a justification by some consultants not to involve them in the management of patients with dysphagia in other hospitals (Horner, 1999). It is, perhaps, ironic that this argument is used given the lack of evidence for most medical procedures. As Fox (1994:10) notes:

The patient is potentially at the focus of organisational contestation, with each specialism attempting to impose its own discursive position at the expense of the other, to establish a position of power and control over proceedings.

Conclusion

At the beginning of this chapter I suggested that evidence based medicine is designed to improve the quality of care by applying a combination of the best available evidence with good clinical skills to treatment decisions. The quality of treatment decisions is seen to improve with increased objectivity and laboratory medicine forms part of the evidence discourse. However, I have shown that laboratory medicine may not necessarily improve treatments, or care. In stating this it is not my intention to downgrade technical medicine, nor am I suggesting it should lose its privilege as a dominant discourse in the management of children, rather my interest is in exposing the limitations of biomedical discourse by highlighting the different discursive frameworks which organise clinical decision making. Moreover, I have argued that clinicians have different perceptions of risk as a result of a fragmented and dispersed duty of care.

Mishler (1981:151) comments on professional attitudes towards tests and investigations and the different cultural medical practices which influence their use:

Thus, although both diagnosis and treatment might appear on the surface to be primarily technical matters, it is clear in this instance that their determinants reflect the sociocultural context of medical practice.

Payer (1989) suggests diagnosis and treatment reflect the core-cultural values of the society in which medicine is practised rather than an application of science, which challenges the view of science as a universal enterprise. Patients in the US are more likely to experience 'aggressive' treatments than in Europe because of the metaphor of the body as a machine that can be overhauled and fixed as well as the greater emphasis on patient/parent rights and the trend toward litigation for non-intervention. Research practice is similarly subject to cultural influences with RCTs informing very little clinical practice in other European (e.g. France), and African countries (Costello and Zumla, 2000).

Dayle and McIntyre (2003), drawing on Foucauldian ideas, argue that interventions use and perpetuate certain kinds of knowledge that are considered prevailing truths. Truth is an example of a technology of power where certain discourses are promoted at the

expense of others. Within the practice of EBM scientific discourses prevail while clinical judgement and lay knowledges remain muted. However, not only do parents subvert the scientific discourse through their resistance and 'non-compliance', but I have also discussed examples of professional resistance to submitting their practices to scientific discourses which serves to privilege their clinical expertise and maintain their authority and autonomy.

These examples serve to illustrate that patient care is more than the application of a series of technical prescriptions, but reflects a 'socially organised practice' (Mishler, 1981:99). Latour and Woolgar (1979), in their ethnographic study of scientists and laboratory life, demonstrate how scientific activities are transformed into scientific facts. They argue that successful science is dependent upon a number of discursive practices such as: alliances with other networks of scientists and powerful groups, the use of rhetorical devices to substantiate truth claims (for example, laboratory equipment) and appeals to authority (e.g. situating facts in existing bodies of knowledge). Similarly, there is a parallel with this construction of science and the clinical care of patients negotiated within institutionalised processes characterised by gendered hierarchies of power and control.

In the next chapter I highlight in more detail some of the contradictory and, subsequently, ethical aspects of care when patients are constituted as research subjects and the difficulties this raises for feminist researchers.

5. The conduct of research practice: researcher positioning, ethics and emotions

Introduction

Feminist researchers have struggled with issues of power and control in research relationships and the associated ethical issues. In this chapter I consider some of the ethical issues I encountered in co-ordinating the clinical evaluation and carrying out interviews with parents, some of who were also taking part in the evaluation study. I aim to explore the dynamics between the researcher, researched and the clinical services, drawing on ideas from psychoanalysis and feminist reflexivity as analytical tools in order to understand more about research relationships and how emotions function in fieldwork (Bondi, 2003; 2002). This process of reflection exposes some of the key tensions that arise when biomedical and feminist research overlap and casts light on the way clinical, ethical and methodological issues intersect and the attendant consequences for researchers, families and clinical practice.

Using observations, diary extracts and interview material, I reflect on my own and families' experiences of taking part in the research. I focus on my relationship with one mother (Ricki's mother) in particular in order to describe how a research relationship developed during the course of the research and how she (and I) constructed different aspects of the research and our relationship within it. I also chose this example because the gastrostomy feeding intervention did not live up to the mother's expectations. I illustrate how negative clinical outcomes can affect research relationships. The selection of this material is not intended to detract from the very positive outcomes children and families can experience following the insertion of a gastrostomy.

Drawing on a psychoanalytical framework, I highlight a number of parallels in the management of emotions in relation to clinical decision making, parental participation in research and my own experiences of co-ordinating the study. In describing these processes I interrogate bioethical frameworks and highlight their inadequacy in guiding

researchers during their fieldwork. I then consider what a feminist ethics of care can contribute to our understanding of research processes.

Theorising emotions in research

A discussion of the role of emotions in fieldwork is not meant to detract from issues of power and exploitation in research relationships, where women are objectified as research subjects. Rather I use emotions and feelings as a resource to disrupt dominant scientific paradigms that separate researcher and researched in the name of a disinterested (masculine) objectifying science.

Bingley (2002:210) argues that both researchers and participants are involved in 'a dynamic interaction' which is rarely neutral. This dynamic begins from the first time parties meet to negotiate participation in the research enterprise. Hunt (1989) suggests that research relationships are likely to mobilise intrapsychic conflict in the form of transferences and counter-transferences. Frosh (1987:77) defines transference in the context of therapeutic relationships as the process whereby the patients' unconscious expectations and fantasies towards others and objects of their past are reproduced and displaced onto the therapist. Counter-transference refers to the (unconscious) feelings the patient engenders in the analyst. While not suggesting the transferences experienced in the therapeutic relationship are the same as in the research context (Hunt, 1989:58), the concept is useful in elaborating on research relationships by emphasising intersubjectivity and challenging the researcher/researched binary.

Similarly, Bondi (2003:68-71) has drawn on object relations theory, and in particular the concepts of identification and empathy, to understand research processes: 'Identification is a process through which the psychoanalytic subject absorbs and incorporates aspects or attributes of others' and this can happen at the level of the conscious and unconscious. Identification can also refer to the 'unconscious expulsion, or projection, of unwanted psychic material' onto others. Empathy involves 'introjecting aspects of the emotional experience of the other, or being receptive to the other's projections'. Of importance is the way these processes facilitate or obstruct

communication and understanding by allowing researchers to 'feel' the feelings (of others as well as their own) but not be incapacitated by them. I illustrate how the conflicts engendered as a result of my contradictory positionings within the research enterprise contributed to my own experiences of emotional 'strain' to the extent that, at times, I felt overwhelmed by them.

Caring, ethics and research

Ethical issues in biomedical research are seen to be the preserve of research ethics committees which, in the NHS, play a role in ensuring that research conforms to certain standards designed to protect research subjects from distress or harm.

Obtaining ethical approval is viewed as one of the milestones (hurdles) in the initial stages of the research process, constructed as linear, logical and sequential. Within conventional research paradigms, once approval has been given, researchers are unlikely to consider the issue of ethics further. If situations or circumstances arise during the course of the research which require researchers to review the ethics of their practice, their concerns are often ignored or assuaged with stock phrases such as: 'the study already has ethical approval' or, 'this is routine clinical practice'. Such statements are designed to deflect criticism and protect the research. Menzies-Lyth (1988) notes the role of institutionalised psychic defenses which function to protect staff and the institution by managing anxiety, for example the frequent rostering of nurses which protects them from becoming too attached to patients. Similarly, the ethics committee serves as the guarantor of ethics and protects the institution and researchers from litigation. Ethical approval therefore is constructed as the 'gold standard' by which responsible research is measured and which is increasingly defined in relation to a bureaucratic procedure.

However, researchers may encounter a number of issues that go beyond the remit of ethics committees that are rarely addressed in conventional accounts of research practice. Researching sensitive topics with marginalised groups (as here with children with chronic illness, disability, life limiting conditions and their carers), for example, is

an area fraught with ethical dilemmas in terms of what we ask of parents and children. Should parents who are dealing with difficult decisions about surgery for their child be asked to participate in research when their time and energy may need to be focussed on considering treatment options? Should mothers who are already spending seven hours a day feeding their child be asked to participate in interviews, or complete food diaries, that make more demands on their time, given the level of detail required, (e.g. estimating weight and size of portions), and which serve to remind them of how little their child eats? Should families be given questionnaires where they are required to think about their child's future when in some cases they have to cope with the present, or where there is uncertainty about a child's longevity? These questions would probably be answered affirmatively within a bioethical framework, the justification being that the research contributes to knowledge and avoids harm in the conventional sense. Approved studies serve to protect researchers but may leave the subjects of research vulnerable and exposed.

Alderson (1990:189) notes the way ethical medicine guided by philosophy and law has been replaced by bioethics, characterised by universal laws and theories of 'duties, utilities, or abstract rights'. As such:

Bioethicists stress the principles of justice, of respect for personal autonomy, of beneficence in doing good and avoiding harm to those affected by medical treatment and research.

Feminists have criticised such approaches as androcentric and exclusionary because they embody male values of autonomy and justice based on abstract moral reasoning (Gilligan, 1987;1982). Women have traditionally been constructed as emotional, unstable (ruled by their hormones) and incapable of rational thought. Constructions of women as 'incomplete men' ruled by their biology for example, have been used to infantilise and exclude women from education, the franchise, and owning property, on the grounds that they are unreliable and unable to make rational decisions (Birke, 1986). Similarly, children are not seen as capable of making rational decisions by virtue of their immaturity and status as 'incomplete adults' (Lee, 2001).

Bioethics, with its emphasis on duties, utility, rights and justice, then, is based on the construction of the subject as the universal, rational male typical of liberal, Western democracies. As such it represents a male dominated ethics which serves the interests of a male dominated science. This construction of the subject is replicated in theories of moral development that position women as morally immature (Gilligan, 1982; Munch, 1994). Kohlberg for example, suggests men and women use different cognitive styles when making decisions. Women, he asserts, fail to achieve the higher stages of moral reasoning characterised by the ability to apply universal principles, objectivity, detachment and an ethics of justice (Gilligan, 1982). Alderson (1990:208) summarises Kohlberg's view of adult morality as 'concerned with impersonal, universal justice. It respects detached objectivity and autonomy, and frames moral rules to protect them'.

Conversely, Gilligan posits a gendered theory of ethics that suggests men and women use qualitatively different moral frameworks. Women, she argues, based on their personal experiences and practices of caring for others, make moral decisions consistent with an ethics of care that requires them to consider the needs of others. As such, women adopt a more relational style characterised by involvement and connectedness with others. Although Gilligan's theory is not without problems (for example, she essentialises gender), she attempts to address masculine bias within the social sciences, where theories, based on all male samples, position women as inferior, or less able, in relation to a male norm or standard.

The effects of investigating sensitive subjects on both participants and researchers are rarely documented in the biomedical literature. With few exceptions (Snowdon, 1997; Oakley, 1992), the psychological distress experienced by respondents as a result of participating in research is rarely recorded, as emotions and feelings are scripted out of most accounts of research practice. Conversely, a number of feminist researchers have drawn attention to the emotional demands of carrying out research with women from vulnerable groups (Einagel, 2002; Whittaker, 1995). The potential for 'emotional strain' on researchers and participants has traditionally been associated with interview or ethnographic methods. However I would argue that the fostering of relationships, and therefore involvement with participants, is more closely associated with interviews

than with experimental designs because in the case of the latter discourses of objectivity preclude the possibility of 'interaction' and 'rapport', at least in theory.

Distress and consent: protecting participants

Anticipating that the interviews could raise difficult issues for mothers I was eager to identify sources of support should the women become distressed as a result of taking part in the interview study. As researchers we need to consider the impact on participants of talking about intimate aspects of their lives, which may include areas they have rarely previously thought or spoken about. The very act of being listened to can unleash powerful emotions and reflections which women may have to deal with long after the interview is terminated. When people agree to take part in research, they may not anticipate becoming distressed. I indicated that participants should only discuss areas they felt comfortable talking about and I also included a warning in the project information sheet to try and prepare women for the fact that they may become upset when talking about their experiences. I qualified this with a statement about people appreciating the opportunity to talk - an assumption that warrants further examination.

Concerns that standard tools, such as those designed to measure stress and coping (see appendix 5 for example), might evoke difficult feelings in women are rarely considered either by researchers or by ethics committees. However, as I will discuss later in this chapter, women did address the questions on stress and coping both positively and negatively.

In trying to identify support I approached the hospital to see if there was a counselling service available to parents. The Hospital Social Work Department told me that the service was in high demand and dealing with parents who may become distressed as a result of taking part in research fell outside the scope of the service. I then wrote to a charity that offered counselling support to families of disabled children to enquire about the possibility of referring parents. I described the interview study and explained that, although unlikely, a situation might arise where a parent felt they needed further

support or counselling in relation to gastrostomy feeding or any other ‘unresolved issues’ about the birth or their child’s diagnosis.

In their reply the organisation offered cautionary advice about my plans to interview parents: ‘even though you say the risk of distressing families is slight, we should not open up that possibility’. The protectionism/paternalism inherent in this statement is illuminating. The organisation appears to construct the research as potentially harmful, which subverts the view that ‘it’s good to talk’. The overall tone was one of keeping the lid on the Pandora’s box, and reflects, perhaps, a professional anxiety about the possibility of unleashing any emotion or distress associated with feeding and disabled children. There may also have been resource issues underpinning their reluctance. My approach may have been interpreted as ‘imperialistic’. Academic institutions are often accused of exploiting the voluntary sector when it comes to research and perhaps it was unrealistic to expect that the organisation would be prepared to deal with the ‘fallout’ from academic research in the absence of any tangible benefit. This example also points to the need to involve voluntary organisations in research as equal partners at the planning stage of research proposals (Craig, 1998).

This discussion about securing support highlights how the onus of responsibility for dealing with distress falls on researchers and makes them responsible for the ‘emotional work’ involved in research. The need for support for researchers working in emotionally sensitive areas has been emphasised by Holland and Ramazanoglu (1994) in their work with survivors of sexual abuse. Whittaker (1995) has also written about the emotionally demanding nature of fieldwork and the lack of formal support available in her research with sex workers. The lack of support for families within the clinical services mirrored my own. For example, I remember one interview with a mother who spoke of her increasing sense of isolation and loneliness. A parallel emerged with my own feelings of isolation within the project and the department where I was based (Neurosciences), where I was the only qualitative, non-clinical researcher and therefore occupied a marginal role. I felt professionally and academically displaced with little outlet for any difficult feelings the research raised for me. Working with doctors, who also had to face the distressing circumstances of child illness and death, meant it was very difficult to raise the issue of support. Additionally, within the dominant

atmosphere of (male) bravado I felt that asking for support would be misconstrued as my inability to cope.

Researcher positioning within institutionalised discourse

In order to gain access to families I initially asked the clinicians involved in their care to discuss the research with parents to see whether they would be willing to participate in an interview. The problems of using gatekeepers in research has been documented (Einagel, 2002) and my study was no exception. For example, a doctor suggested to one family with a fraught history of interactions with the clinical services that they should participate in an interview as a means of 'getting their own back'. Presenting the research in this way was somewhat misleading, for how would it help the family to 'get their own back'? Would an interview really empower parents by giving them a voice, and was it appropriate for me to become involved if families were in the process of considering legal action against the services?

Not only did I have concerns about how parents might perceive my role (whether independent, or representative, of the service), I was uncertain about the boundaries between research and clinical data in relation to the issue of litigation and whether data collected for research purposes could be drawn upon to support a case conference, particularly as some of the clinicians involved in the research were also providing a clinical service to the families. Robinson (1996) has cited examples where information obtained from psychological tests as part of a research study resulted in the inclusion of pejorative reports in patients' records.

In this particular case, although I entered into negotiations with family members about how we might conduct an interview, so that they felt they had some control over the research, they were suspicious of the aims of the study, believing that clinicians were only interested in parental views in order to manipulate them into consenting to their child having a gastrostomy. This positioned me into having to defend my research, and in all fairness I could not deny that clinicians may have wanted to use information in this way. I eventually decided against the interview with this family as it seemed too

‘politically sensitive’, enmeshed as it was in a web of grievances, accusations and mistrust. At the same time, the family, on the advice of their solicitor, also decided against taking part.

Contradictory positionings

The above discussion has served to highlight some of the ethical issues concerning the positioning of researchers within institutionalised discourses. In the earlier days of the study I did not observe the clinical consultations, preferring to be seen as separate from the service. I later changed this strategy as I felt it important to observe the consultations to see what information, or explanation, was given to participants about feeding technologies and surgical procedures. I was usually able to identify families considering gastrostomy surgery from the referral letters to the consultants. I then introduced myself to the family while they were waiting for their appointment with the surgeon and asked their permission to observe the consultation. However, given that a gastrostomy was not always indicated, nor agreed to by all parents, I later decided to observe the consultation and wait for the consultant to introduce me to the family pending the outcome. These different strategies reflected a constant tension throughout the life of the project about my role and positioning and desire to be seen as separate from the clinical service and impartial with respect to the issue of gastrostomy.

This tension was also apparent in the way I introduced the study, using ‘position statements’ like ‘the clinicians’, or ‘they’ in order to distance myself from the clinical service, and ‘we’ when I reverted back into the role of representative of the project. Sometimes the consultant would say to the parents ‘you’ve asked us questions, now we would like to ask you some questions?’, or, ‘we are carrying out some research and we’d like you to help us?’ As researchers we might feel some unease about such a direct link between clinical treatment and research, which raises the issue of whether parents felt they had to participate out of gratitude even though they did not have to consent at that point.

The research raised several ethical dilemmas in terms of what I should disclose to families about my role and position. For example, I always told the families that I was

a non-clinical researcher and therefore not involved in their child's clinical care. However, the clinicians involved in the delivery of the service treated me as part of the team and would often informally discuss details of families under their management with me. There were therefore 'grey' areas where information about families were exchanged, albeit inadvertently. I also had access to patients' notes and had potentially more background information about families than might have been revealed in an interview by participants (I read the notes to obtain information about children's weights and diagnoses). Sometimes there was sensitive information contained in the children's notes about allegations, or confirmed episodes, of non-accidental injury, or information about the parents and their domestic arrangements. Further, the consultants often introduced me to the families as a 'doctor', 'nurse' or 'an expert' on gastrostomy feeding, which further complicated families' expectations of my role and function. In practice I had no power of referral and as the emotional and practical support parents often required was lacking I increasingly found myself performing the role of advocate for families as the research both exposed, and fulfilled, the gaps in service provision.

Coghlan and Casey (2001) suggest professionals who carry out research in organisations where they work have to mediate between a number of competing interest groups. Their organisational roles as professionals, governed by hierarchy, can present them with role conflicts when engaging in research because of divided loyalties and dilemmas of identification. Einagel (2002) also notes the ambiguous and doubled positionings of researchers when conducting ethnographic research. My position as a non-clinical researcher was one of 'outsider', which was at times advantageous because it meant I fell outside of the hierarchy of medical control. However, parents viewed me as an 'insider' because of my knowledge about gastrostomies. Further, by virtue of my position, I was allowed access to information and places that parents were not. For example, I often entered the operating theatre to ask for blood samples to be taken and was invited to observe gastrostomy surgery, which placed me as a (dubiously) privileged insider. Given my position as a white, 'middle class', university-educated researcher, this positioned me as an 'insider' with respect to societal norms and an 'outsider' in relation to the women from black and other minority ethnic and, working class backgrounds (Willot, 1998). This highlights the multiple positionings of

researchers within academic discourses and in relation to participants' race and class. Researcher positionality therefore is 'neither fixed nor predetermined' (Lal, 1996:197).

Great expectations: research, care and service delivery

As researchers, we have specific agendas in terms of what we expect to gain from our research activities, which may include the desire to contribute to knowledge, and in my case, obtain a PhD. Of interest is whether research participants have a particular agenda or fantasy about the research and whether they feel they will benefit from participating in some way. Many families appeared more than happy to participate in the study. One father replied: 'we're in for it one hundred per cent', believing that had the research already been carried out they would be better informed about feeding technologies. Families also stated that as they had benefited from health care, they would be happy to take part: the gratitude factor. Another mother however, complained after arriving at the hospital, that the research team were not there to meet her equating participation in the study with an expectation of preferential treatment. Other families were less enthusiastic or non-committal and I was usually able to tell who would be likely to enrol. Some were so distressed and tearful, confronted by the recommendation that their child needed a gastrostomy, that it was inappropriate to discuss the study with them. Again I found myself offering a sympathetic ear, trying to answer their questions and, where appropriate, allay their concerns.

Ironically a number of parents looked on the research as a source of support, as did the clinicians, although this was not the intended aim. Indeed one consultant sometimes suggested to the families that they take part in order to get support. If parents felt supported by the research this was incidental, for in positivist terms if parents found the research or research team 'supportive' this would be construed as a confounding variable as availability of support was one of the variables being measured as part of the evaluation!

This next example describes how one mother used the research to her advantage as a means of obtaining support. It describes what happens to research relationships when

the intervention, service delivery or the researcher does not live up to expectation. Phoenix, (1994) reports on how 'rapport' increased as a function of frequency of contact in an interview study with young mothers. I am aware that the term 'rapport' is poorly defined and understood and could reflect a number of processes such as agreement, compliance, or a shared value system. Further, rapport may be dependent upon a number of factors and is not intrinsic to any one method. It may depend on whether participants perceive you to be sympathetic, trust you, like you or think you may be helpful to them in some way and the concepts of empathy and identification discussed at the beginning of this chapter are relevant here. To some extent, repeated contact with families either by telephone, or during hospital appointments provided an opportunity for rapport. However, I also felt that rapport was related to the outcome of the intervention, which I discuss next with reference to Ricki's mother.

Ricki's mother

Ricki's mother was a young British Asian woman and had quite high expectations of both the intervention and the research. It is worth focussing on my relationship with her because: she agreed to take part in all aspects of the research and I interviewed her twice in her home; she telephoned me on a number of occasions; we had contact at the hospital when she attended appointments; and Ricki did not gain weight, which was the main reason for having the gastrostomy.

As the following extracts from the pre surgical interview with Ricki's mother suggest, she was enthusiastic about the research because she felt participating would facilitate her understanding of the intervention ('I can learn something from it') and provide her with someone whom she could 'be with' and 'talk about gastrostomies':

And then I saw you, you said to me that you're doing this research, it's about gastrostomy and about children who are going to have it done. And then I thought you said you could either say yes or no, you don't have to do this and this and that, but then I thought no I think I should do it because I can learn something from it as well because, I don't really know that much about gastrostomies ...then when I saw you you said 'I'm doing this research.' And I said 'OK I'll do it.' Because I wanted someone to be with me in that sense and talk about gastrostomies. [Ricki's mother, 1/2]

In this next extract, the mother again talks about the need to know more about the procedure and to have someone she can talk to about the intervention:

M: And then I said, you know then I started to fill out those questionnaires and then I met you a few times at the hospital and I thought that's good because it made me feel a bit better because I knew there was somebody there that if when I see [the Consultant] I'll see Gill, or I'll see the other lady, I've forget her name, and I said I'll see them and then I'll feel, I'll get into the understanding stage of it, I can learn from them and they can learn from me as well. I told my husband when I came home that day, I said 'I'm going to do a research about the operation as well.' And he said 'That's good. Are you sure?' And I said 'I think that's good because I want somebody to be with me in a way like that.' I know you're not a doctor or you're not, you said you're not a doctor, I don't know, are you a doctor?

G No I'm not a doctor, I'm not a clinician at all, no.

M: I thought she's not a doctor but you know I think about the operations, like you know, like the questions that you're asking me, you know even though I think about them, and I just thought I would just be getting a bit ... um ... some sort of support, I don't know. Some sort of, I could just say what I want to say and I could just have a friend as well. But there's not many people that sort of, I've got friends and everything, and I've got family, but sometimes you want to talk about, like you know about the hospital, you know about the questions and the questionnaires and you've seen children that have had the operation done and I thought it's nice to be talking to Gill and doing the research because ... I might get some information and help. Not help, yeah, some support, some guidance. [Ricki's mother, 1/2]

Again the mother talks about her need to have someone to talk to, a 'friend' who has an interest in the field of tube feeding. The mother clearly expects that she will get some 'help and guidance' as a result of taking part in the study and might learn more ('information') about hospital procedures. The relationship is construed as a symbiosis, or exchange, rather than one of exploitation: 'I can learn from them and they can learn from me as well'; 'I could ask you something and you could ask me something'. The example is of interest because it clearly shows the lack of provision of specific aspects of care from the clinical services: adequate information about the procedure and support in terms of having someone to talk to who is also interested (indeed someone who has a vested interest). Participating in research appears to fill the gap, superficially at least. Although the mother knows I'm not a doctor (and she asks me to clarify this by asking me directly), she positions me as an 'insider' who has access to knowledge that she doesn't have access to ('you know about the hospital...the questions, you've

seen children'). By participating in the research she is seeking to gain access to this insider perspective.

The need for support was apparent when Ricki's mother contacted me by phone to inform me that the appointment for surgery had been cancelled due to a bed shortage. She expressed her disappointment as the hospital had been unable to confirm a date for the rescheduled operation. The mother constructs her distress in terms of a psychological discourse – 'psychologically preparing herself for the operation'. By suggesting that the cancellation has put her back to the decision making stage of thinking about whether Ricki needed the gastrostomy, she constructs herself as a rational (masculine) decision maker, re-charting a decision curve.

Whether Ricki's mother had contacted me believing I was in a position to influence her child's admission for surgery was unclear. Families may have assumed I had some control over procedures, which was not the case. In fact the cancellation of hospital admissions due to a lack of availability of beds and staffing shortages was common. Cancellations of surgical operations or clinic appointments had an impact on the research because of the frustration parents expressed to the research team. Some parents even considered withdrawing from the research altogether.

I had another phone call from Ricki's mother not long after the operation. Again she was very distressed because of Ricki's 'strange' behaviour which she attributed to the effects of the operation and the gastrostomy tube. She described the hospital staff as unsympathetic for not responding to her concerns. She expressed her need for support and understanding and her regret at having consented to the operation. Although she understood that I was not a doctor she wanted to 'let off steam'. Her 'frustration', originally directed at the doctors was re-directed towards me. Again I found myself in the role of advocate, offering advice and support about the best way of proceeding. The mother used the research as an outlet to channel her concerns and the idea that the research relationship was helpful, rather than exploitative, appears to hold.

The timing of this phone call from Ricki's mother is interesting because she steps out of the subject position of research participant, that is, to be contacted by the researcher in

accordance with the research specification. Rather, she thought it appropriate to talk to me about how she was feeling at that moment and not according to the time frame, or method, specified in the research design (i.e. by questionnaire sent every three months). She had interpreted the research as a study about feelings and coping. However, it was unclear whether her phone call indicated her investment in the research, a need to talk to somebody, a veiled complaint about the hospital, or a general feeling of powerlessness in the face of the hospital's lack of response to her concerns.

The symbiotic nature of the research relationship did change over the next few months. At the follow up interview it was apparent that Ricki's mother felt aggrieved that she had not been given sufficient information about the side-effects of the operation. She complained that no one had really sat down with her to explain what could go wrong, including me. Although she knew I was not involved in her clinical care there was an expectation that I should have told her more.

Oakley (1981) suggests researchers should use their position productively by giving information to participants. Generally I was happy to respond to parental requests for information, but explaining possible side-effects and complications was always a difficult area, particularly as I had never had any official training, was not responsible for children's clinical care and because I wanted to maintain my independence from the clinical service, although this became increasingly difficult in practice. While I was careful not to give the impression the operation was risk free, I preferred not to go into too much detail to avoid giving conflicting information. Although I had access to information as an insider, there were specific aspects about surgical decision making that were not particularly transparent to me. In these cases I generally advised parents to speak to the doctors responsible for their care. I was also mindful that if I did not answer parents' queries that they might feel 'fobbed off' given they were experiencing difficulties obtaining the information they required. Indeed if the reason for taking part in the research was to learn more about the procedure, which appeared to be the case with some parents, then in their eyes I was duty bound to give the information as a 'representative' of the service. Consequently I increasingly found myself in the role of information provider as I became further enmeshed within the clinical service, and

clinicians were only too happy for me to assist in this way given the constraints on their time and resources.

After the operation Ricki's mother asked about other children in the study and how they had fared. I spoke to her about one little girl (without naming her) in order to reassure her that she was not alone in experiencing difficulties and that other parents were also having 'teething' problems (although I'm not sure this was reassuring). Some time later Ricki's mother again enquired after the little girl. Sadly the girl had died of unrelated causes. However, not wishing to alarm her, I told her that the child was doing well. Miller (1998) cites examples where she thought it inappropriate to disclose information to participants. There are therefore situations where transparency in research relationships may not be advisable.

Although I could sense an uncomfortable parallel with instances of medical paternalism where patients have been denied information, the justification also being the need to protect them, I did not feel it was appropriate to tell Ricki's mother about the death of the child in the study because of the anxiety this may have provoked. Further, the excuse of denying patients information in order to protect them is used to protect medical practice. I also felt an acute sense of taboo surrounding the subject of death in young children. My own distress on learning of the death of the child forced me to reflect on whether underlying my non-disclosure was my own discomfort reflecting a need to keep the lid on the 'Pandora's box'.

Twelve months after the operation I met Ricki's mother by chance in the outpatient clinic. I asked her how she and Ricki were although technically she had finished participating in the research. She told me she was concerned that Ricki had not gained any weight and had spent more time in hospital after the operation than before it. When I asked her about good and bad days she generally felt that the good ones were few. As I was writing down these experiences (a coping strategy perhaps), she enquired whether this was another survey. I immediately felt that I had chartered an unwelcome intrusion. Unlike before, where she rang me to discuss her feelings, she was less enthusiastic about my documenting Ricki's progress now. It was as if the research no longer served a purpose. Her silence and resistance to submit to the research gaze,

subverted the researcher-researched binary (Bhavnani, 1990). Lal (1996:207) suggests acts of resistance can transform research relationships: 'Here the researched Other acts as Subject, and the Other is transformed into the knowing, acting, self'.

I interpreted Ricki's mother's resistance as a projection of her anger/disappointment. My response increasingly was to avoid her, which illustrates some of the difficulties of ending research relationships when there are unresolved issues for both researchers and participants. This suggests a parallel between Ricki's mother's powerlessness in the face of her child's illness, and my own at not knowing how to respond to her. Her willingness to engage initially with the research contrasts with her disengagement toward the end of the project and my own disengagement with her. Her silence mirrored, perhaps, my own resistance against the (gendered) requirement to be 'emotionally present'. Bondi (2003) notes how structural differences have the potential to disrupt the possibility of identification and empathy between researcher and researched.

The experience also led me to rethink the ethics of some of the more informal aspects of our fieldwork. For example, parents may be unaware that our reports contain information about telephone calls, conversations in clinics and corridors, informal observations etc. Ricki's mother did enquire whether I was writing things down when she telephoned me, and I usually asked her permission. However, these 'informal' aspects of research practice do need to be discussed and negotiated with parents and we should not assume that we have the right to include and analyse every 'sound-bite' our participants offer because they have consented to take part in our research. The example also attests to how commonsense representations of research separate technical from relationship aspects and how this can lead participants to be implicitly deceived or exploited.

It is unclear whether men viewed the research as a source of support. The majority of the interviews were conducted with women who, as the major caregivers, completed the majority of questionnaires. In six of the interviews a male partner was present. In four of these the fathers were present from the beginning of the interview, although one sat silently throughout and made no contribution, as if to offer the mother a protected

space. As the major caregiver, this was her opportunity to talk about her experiences. Another father however talked incessantly and dominated the conversation.

One father in particular was appreciative of the fact that I had visited the family at home, stating that no one else had made 'the effort' to find out about their experiences. The family lived in a remote rural location. It had taken me the best part of the morning to get there by train and taxi (due to lack of public transport). I knew this would not go unnoticed by the family - a researcher from a London hospital (a centre of excellence, and highly regarded by many parents) held a certain cachet, particularly as many families complained about the care they received at their local hospital, either at the birth of the child, or since. However I felt disingenuous. I had come to visit as part of a research project, which would also form part of my PhD¹³. My visit, for which I was paid, was interpreted as an act of generosity, an act of caring.

Earlier I wrote of how one charitable organisation cautioned against interviewing families because of the potential harm of distress. The organisation's concerns were not supported by this family. They welcomed the opportunity to talk about a number of unresolved issues about the death of one child and another's disability. It is clear that parents use research in different ways: as a means of obtaining information, clarifying procedures, gaining support or airing grievances as well as a desire to help. As such, blanket criteria about how research should be conducted may not always apply. I discuss this at the end of the chapter.

Standard tools in clinical evaluations

In chapter 2 I discussed how feminism has become inscribed within particular research methods such as qualitative interviews which allow women to express their views in their own terms, compared with attitude scales which impose or fix meanings. Surprisingly, Ricki's mother commented on the 'therapeutic' value of completing

¹³ On the advice of the clinicians I did not tell people that I was using the material as part of a PhD because the work also formed part of a funded study. However, ethically, this should have been disclosed to parents.

particular psychological scales incorporating items about stress and coping and different aspects of her child's daily management (see appendices 5 and 6):

M: yeah from your questionnaires I just make, seeing how I was. From those questionnaires I was looking at how I was feeling. So that was good that the research came in at that time because I was bringing myself, my feelings out in a way and that was good.

G You're saying that the questions helped you to bring out your feelings?

M Yeah. They helped me because if those questions, if I had never seen those questions and from the time I saw a doctor, [the Consultant] until the operation day I think I would have been a bit lost, a little bit lost but. No because they helped, saying yeah I feel this, I feel this, I feel this and when I ticked them then you feel good, like you feel a bit like you've, like you've spoken to someone in a way, but you've just ticked them on sheets, and I was showing them to my husband as well and he was saying yeah, yeah, he feels that, he feels that. So it was like therapy for us and it sort of gave us some time, passed time to the operation like we were looking at Ricki, looking at the questionnaire and the food bit was a bit difficult because Ricki doesn't eat and that bit was a bit difficult, I didn't know how to fill those bits out properly because he doesn't eat that much. Yeah that's all really. [Ricki's mother, 2/2]

In psychotherapeutic discourse the questionnaires function 'to hold' or 'contain' the family while awaiting surgery ('so it was like therapy for us and it sort of gave us some time, passed time to the operation') and draws on Winnicott's notion of a 'facilitative environment' provided by the mother to her child (Bingley, 2002 quoting Phillips, 1988). The questionnaires therefore serve as a 'stop-gap' and are equated with having 'spoken to someone'. However, it is possible that the questionnaires confront women with their own feelings around caring and coping and validate their experiences by publicly acknowledging that other mothers are in a similar situation. In asking women to rate particular statements (for example, feeding has been easy/difficult), this may provide them with an opportunity to acknowledge that they are experiencing difficulties caring for their child. An admission that is rarely expressed given that the prevailing discourses of mothering construct the ideal mother as one who is competent and selfless and who places her children's needs above her own (Lewis, 1991).

The admission that caring for a child might be difficult is another taboo subject. However, a written statement, which carries a certain authority, may validate women's experiences and give them permission to own 'forbidden' feelings around caring for children which helps break those taboos. The statements may reflect feelings that

women have experienced but have less scope to articulate, or disclose. One mother for example, returned the questionnaires with a note saying 'thank you' attached while another confided to a member of the research team that 'no one had ever asked her those questions before', again implying that she had also derived some benefit from seeing or answering them. Here the standardised character of the technique communicates the general, rather than the unique and special, character of the difficulties women experienced.

Not all women reported positively on their experiences of completing questionnaires however. One statement in particular, which pertained to the need for institutionalised care for their child at some point in the future (see question 5, appendix 5), provoked comments:

some of the questions were asking, like to me they were asking things that you would make decisions maybe further down the line. And I found that quite difficult to think, I can never think about not wanting, I know it wasn't asking us you wouldn't want him, but some of the questions were 'maybe would you think about residential care for your child?' and to me that's like saying that I can't do it any more, I need someone else to do it, and I think that's quite upsetting, for me it was quite upsetting to think but then that's how I am. On the whole I found them quite useful questionnaires to fill in. [Jack's mother, 2/2]

Again discourses of sensitive mothering (which I discuss in the next chapter) which position women as competent, capable and devoted make it difficult for a woman to think about placing a child in residential care since this would be an admission of failure. One mother indicated that some of the questions referring to her child's future had 'brought tears to her eyes' as they had forced her to think about issues she had not previously considered. However, she also reported finding the questions beneficial, helping her to focus on her child's long-term care needs.

As part of the clinical evaluation, it was customary to carry out a medical assessment with parents three months after surgery which usually took the form of a telephone interview. The questions routinely asked about medication, chest infections, illness, feeding and issues relating to the management of the gastrostomy. One mother reported that her child had developed secretions (excessive pooling of saliva) and drooling which had become a major problem. She attributed the increased drooling to the

gastrostomy and described her child as 'constantly bubbly and distressed'. She reported that although the operation had been successful, because the child was no longer aspirating and not experiencing as many chest infections, this was 'dampened by the saliva build up':

Before [there was a] cycle of poorly-well, now she's constantly fighting against the saliva build up. It's really disheartening, I'm upset about it...it's getting worse. I feel so helpless, I don't feel I can do anything about it. [Joey's mother, telephone interview 3 months post surgery]

The mother reasoned that whereas the chest infections could be treated with antibiotics, it was unclear whether there was a solution to this new problem. The 'saliva production' had been re-categorised, and therefore marginalised, as a medical rather than a surgical complication which meant it fell outside of the surgeons' remit (Fox, 1993). Her sense of helplessness again mirrored my own at not knowing how to respond to her distress:

It's hard to think that this is Joey. We're in another ball game. This is how she is, distressed every day rather than when she had a chest infection. But the operation was successful. [Joey's mother, telephone interview 3 months post surgery].

In cases like this I usually tried to be optimistic by suggesting that things might improve with time. However, such platitudes seemed unsatisfactory. Trying to complete questionnaires about health and expenditure when parents were distressed was also difficult knowing that the questions may not be relevant, nor of interest, to the families faced with the specific problems they were experiencing. Again I felt a conflict between the demands of the research, the need to complete the assessment, and trying to respond sensitively to the mother's distress.

I experienced similar tensions with members of the project team in getting them to comply with the research in terms of paperwork and assessments of children which they invariably had to 'fit in' with their clinical duties. This often resulted in long delays for families in the outpatient clinic while they waited to be assessed. In the context of a pressurised clinic with a hungry, screaming child and distressed parents,

who needed to leave because of child care or employment commitments, issues of emotional transference also extended to members of the research team!

At the six month follow up I obtained Joey's mother's permission to record the 'exit interview'¹⁴ as I felt it was important to get her views in some detail. The child's grandmother accompanied her. Joey arrived on a stretcher as the family felt the best way of controlling the drooling was to keep her in a lying position. Part of the exit interview was to ask whether the parents felt they had made the right decision for themselves and their child. The following extract illustrates the mother's difficulty in responding to the question through her reluctance to be drawn on the issue:

- G: So do you think it was the right decision for Joey then, you know, now, looking back, was it the right thing for her?
M: Mmm (non committal)
G: What about for you?
M: Um, not really, no. I mean, the feeding's handy but actually, for our home life, although you've got the ease of that, umm, we haven't had the benefit at all, because we've just been so restricted to where we can now go as a family, umm, no. [Joey's mother, exit interview, clinical evaluation]

Ethically I found the questions about whether the parents had made the right decision difficult to ask where the outcome had not been as favourable as expected. They were difficult to ask as I knew from the interviews that mothers had often agonised over the decision for their child to have surgery. My discomfort related to a concern that I was reproducing the discourse of blame (a theme which I take up in chapter 11) by posing the question of whether they had made the right choice, given the received view that a good mother always makes the right decision!

In contrast to Ricki's mother, despite the complication Joey's mother felt the operation had been a success and was happy to let me know informally how they were getting on and whether they would go ahead with another operation recommended to ameliorate the saliva production:

¹⁴ The exit interview was a 6 month follow up interview which formed part of the clinical evaluation where parents were asked about the advantages and disadvantages of gastrostomy feeding in a semi-structured interview. Some of the questions were repeated in the in-depth interviews.

Of course, sure, yeah. I mean, it would be nice to say, yes, I can see the end and I can see the major benefit, yeah I would like to be able to say that. But she hasn't, no. Cos she's well, and yet I can't do as much as I was doing with her before, which is crazy really, because the operation's so successful in its own right [Joey's mother, exit interview]

Scambler (2002:112) notes the way illness narratives are informed or 'contaminated' by the expert cultures of medicine. The mother's comment that the operation had been successful, despite the fact her child's health has generally deteriorated, is indicative of the colonising properties of medical discourse. Further, given the gratitude factor and unwillingness to make negative comments, families may well respond in terms of what they think we want to hear as 'representatives of the service' (i.e. that the operation was successful). Whereas Ricki's mother blamed the surgery for her child's distress, Joey's mother separates the 'side-effects' from the apparent success of the operation. Here the mother reproduced the dualistic construction of the main/side-effects discourse as a key artefact of medical discourse.

Parents, particularly mothers were very aware that they were responsible for making the right choice (as 'good parents' always make the right decision) but, constructing the decision in terms of binary outcomes, when some matters are not susceptible to a binary 'right/wrong', 'good/bad' conclusion, is an oversimplification (Nicolson, 2000). In the exit interviews of the clinical evaluation for example, 93 % (57/61) of parents reported the decision to proceed toward a surgical solution had been the right choice for them and their child, but many framed their response within the context of there being little alternative as illustrated by the phrases, 'but we had no choice' or 'but I'm not happy about it'. This highlights how inaccurate survey questionnaire analysis can be where respondents are presented with a forced choice with little opportunity to expand on their comments. I return to the issue of choice in relation to decision making in the final chapter.

Conclusion

Research in the NHS is increasingly conducted by researchers on externally funded contracts or by clinicians operating within a research-practitioner model, often within

the context of obtaining a higher degree. I have argued that such configurations can be problematic because of the issue of researcher positioning and the conflation of research and care. I have also highlighted the dynamic between provider/recipient of care and researcher/researched within an institutionalised context. I have discussed the difficulties of working as a feminist within institutions where the dominant research discourse is one of knowledge production abstracted from its emotional context. The discourse of objectivity requires the researcher to subordinate her emotions, and those of the participants, to the requirements of the study in order to protect the integrity of the research.

Alderson (1990:155) notes the conflict inherent in medical care that is constituted as both a science and as a caring profession: 'The patient is used as a research subject in one setting, and treated as a vulnerable dependant in the other'. Researchers are required to mediate between these different clinical and research discourses which raise a number of political and ethical issues with consequences for researchers, children and their families. This not only raises issues about supporting families participating in research as part of a clinical intervention, but points to the need to identify appropriate models of clinical, in addition to academic, supervision for researchers and is discussed in the final chapter.

Biomedical ethics serves to protect the research enterprise with an 'ends justify the means' type philosophy, which supports research that contributes to a universal knowledge. If care is compromised en route this is justified along the utilitarian principles of the 'greatest good for the greatest number'. This was particularly the case with the food diaries, which collated data on children's nutritional intake which were used solely for the purpose of research and were not integrated into the child's clinical care. If children were under or overweight this was treated as a research finding in itself.

Another justification for not intervening in the children's clinical management was the need to avoid making demands on an already over-stretched service, particularly when the care should be provided at a secondary level. The fact that many parents did not have access to dietetic support locally was treated as a further research finding, rather

than a need for a dietetic intervention. Undoubtedly it would have been impossible to transfer all aspects of children's care to the hospital because of the nature of the referral process and the contracting system and because of limited staffing resources. Inaction in research is often justified on the grounds that as research is different from treatment it does not require the same standards as clinical care (Hood, 2003). Professionals maintain their power base in institutions by subscribing to particular myths, costs, efficiency and lack of time being examples (Wodak, 1996). However, the current NHS, driven by standards, charters and performance ratings, attests to the material basis of these myths (Willig, 1999). Notwithstanding these arguments, I felt the resource issue was an 'accounting' practice used by professionals to justify their inaction and to protect their workload (Garfinkel, 1967). As such these practices constituted part of the psychic defense of the institution (Menzies-Lyth, 1988).

I have demonstrated that research ethics committees operate within a framework of detached ethics, which frames consent according to a priori, universal principles. I have also demonstrated that difficult ethical issues cannot always be anticipated at the start of the research, but need to be negotiated during the course of the fieldwork. A situated ethics resonates with the idea of situated knowledges in recognition that knowledge is produced within social and cultural contexts. Vivat (2002) argues that only by attending to the local, particular and specifics, can an ethical perspective be formulated. I return to this theme in the final chapter.

I now move on to the next chapter where I examine women's accounts of caring in relation to infant feeding practices.

6. The sensitive mother: women and feeding

Apart from the actual bearing and suckling of children, there is probably no act which better epitomises the maternal role than the preparation and serving of food [Newson and Newson, 1970].

Introduction

If as medical and psychological discourse suggests, women find feeding a disabled child stressful, why do women spend prolonged periods of time orally feeding children in the face of an alternative method – feeding by tube?

In this chapter I explore feeding and feeding relationships in the context of disabled children. Children sometimes stop feeding orally following the insertion of a gastrostomy for reasons that are poorly understood. Mothers in the study raised concerns about the possible loss of oral feeding following surgery, which was viewed as having a range of psychosocial effects for both parents and children. This chapter explores the meaning of food and feeding and the ‘loss’ of oral feeding in relation to dominant discourses of mothering and child development; themes which will be revisited throughout this thesis. Drawing on the accounts of three women in particular, I examine how they construct their relationships with their children around mealtimes and feeding. By locating their experiences within a historical and cultural context I hope to challenge the naturalised mother-child bond more commonly associated with discourses of nurturing. This is reflected in changes in infant feeding practices, which I also discuss. I argue that contemporary mothering is constituted by a number of discursive practices, for example feeding, bonding and playing, which, far from being natural, serve to regulate women and mask relations of power and domination.

Women and feeding

Women have a distinctive cultural relationship to food, feeding and feeding others, breastfeeding being the most obvious connection (Heenan, 1996) and stereotypes about

Jewish and Italian 'mamas' feeding their children also spring to mind. That food is used symbolically in maintaining and celebrating relationships is evident; the old adage- 'a way to a man's heart is through his stomach', for example, reflects the importance attached to a woman's culinary skills, which have traditionally been used as a measure of her worth as a wife and mother. The fact that women increasingly take an active role in the labour market means the pressure on them to excel in the kitchen is perhaps less of an imperative, although they are still expected to have a knowledge of nutrition and to keep the family healthy (Department of Health, 1999). In particular, in low-income families, the pressure to perform culinary miracles in the context of limited resources remains.

The belief that feeding is fundamental to the mother-child relationship, and in particular, the emotional state of the infant, is informed by a psychodynamic perspective which draws on object relations theory (Riley, 1984). However, appeals to the naturalised mother-child bond fail to consider that many aspects of infant feeding are socially constructed. For example, campaigns such as 'breast is best' assume breastfeeding to be natural (Bowes and Domokos, 1998), and yet in contemporary Britain it is adopted by predominantly white, middle class women (Office for National Statistics, 2000). The Department of Health recently reported that only one in five mothers fed their babies solely on breast milk for six months as recommended by the World Health Organisation (Carvel, 2002).

By contrast, bottle-feeding was regarded as a status symbol in the US in the forties because of its association with wealth (Newson and Newson, 1974). Similarly, the use of wet-nurses, with their class and colonial associations, suggests that far from natural, both the mother-child bond and infant feeding practices are socially, historically and culturally variable, as well as gendered, raced and classed.

Women's responsibility for feeding begins at birth with breastfeeding. For example, 'La Leche League', an organisation established in the 1950's to promote and support breastfeeding, reinforces the association between being 'a good mother' and breastfeeding (Bowes and Domokos, 1998). Newson and Newson (1971:36) in their study comment on the guilt women felt at not being able to breastfeed, which was often

portrayed in women's magazines as a child's 'birthright'. Interestingly La Leche League promote breastfeeding as the 'woman's right'. Moreover, in their web page they invite women to acquaint themselves with a number of facts about the benefits of breastfeeding apparently including stardom, by quoting a number of famous people who were breastfed (1. The Queen, Madonna, Mrs Thatcher and Pamela Anderson all breastfed. 2. Basketball superstar Michael Jordan's mother breastfed him until the age of three and credits it with turning him into 'the athlete he is')¹⁵.

The advice also confronts women who are concerned about their 'figures' with the fact that breastfeeding women regain their pre-pregnancy figure sooner than women who bottle-feed. There are also a number of other benefits listed, including a boosted IQ score (breastfed babies score on average 5.2 IQ points higher than those bottle-fed) and health-gains (breastfed babies are at less risk of gastro-enteritis, respiratory and skin complaints). We also learn that a failure to breastfeed could jeopardise a child's life (WHO/UNICEF 1996 estimate that 1.5 million babies worldwide die each year because they are not breastfed¹⁶). Finally, for women with silicon implants, they too are encouraged to breast-feed (point 4 - there is ten times the amount of silicon in formula milk than a mother with implants breastfeeding). By implication, women who do not breastfeed are harming their child's health or cognitive development. Further the reference to silicon in formula milk can only raise anxieties in women who have been unable, or who do not wish, to breastfeed.

This is not to undermine the message that breastfeeding is good for both mother and child, but rather to point out the guilt, and sense of failure, many women feel when they do not, or cannot, adhere to the advice to breastfeed. Further the advice fails to address the social context of feeding decisions in a culture where it is more acceptable for a woman's breasts to appear on page three of a popular tabloid newspaper than breastfeed in public. Indeed Henderson et al., (2000) note that with very few positive references to breastfeeding in the media, women receive little encouragement or support. The advice to breastfeed also fails to recognise that women's subjectivity is multiply positioned by discourses of sexuality, reproduction, and care. Hence, the

¹⁵ (La Leche, GB [online][cited 16-04-01] <www.LaLeche.org.uk>),

¹⁶ Due to contaminated water in breast milk substitutes

claim that women regain their 'figures' sooner after breastfeeding nicely indicates the confounding of these issues, as with the attempt to 'include' into this detail women with breast-implants.

In order to understand the reason why women's subjectivity is so inextricably linked with feeding and nurturing, we need to look at the mothering role and how this has been socially, culturally and historically constructed.

In the next section I examine in more detail the commonly held belief that feeding is fundamental to the mother-child relationship, particularly in the early years, a belief which as I have already stated is informed by psychodynamic perspectives and draws heavily on object relations theory (Briggs, 2000).

The social construction of mothering: bonding and the sensitive mother

The focus of development on a 'two person rather than a one-person psychology' was a turning point in the field of child development (Briggs, 2000:60). Winnicott's (1964) famous claim that 'there is no such thing as a baby.... a baby cannot exist alone, but is essentially part of a relationship', privileged the mother-child relationship¹⁷. Similarly, Bowlby's studies in the 1950's on the effects of institutionalised care on children orphaned or separated from their families forged a link between maternal deprivation and children's mental health: 'mother-love in infancy and childhood is as important for mental health as are vitamins and proteins for physical health' (Bowlby, 1990:240).

The post war emphasis on children's psychological welfare, for which the mother was held responsible, contrasted with the role of the family pre 1940's, where the economic welfare of children guaranteed by the father was stressed, suggesting children's needs,

¹⁷ Psychology 284 Counselling And Therapy [online] [cited 16-09-03]
<http://www.worc.ac.uk/departs/psycho/UG_Courses/Archive/2001-2002/Psy284/Lecture4.html>

and the person identified as best able to provide for them, have varied historically (Lewis, 1986).

In the post war era the mothering role became increasingly defined in 'terms of children's needs and propensities' (Urwin, 1985) as mothers were held responsible for children's emotional development and a critical influence on their child's life (Woollett and Phoenix, 1991). Psychodynamic frameworks have also influenced approaches to feeding difficulties in children by emphasising the emotional qualities of the feeding relationship (Briggs, 2000). This stems from Kleinian theory where feeding was seen as crucial to the emotional state of the infant (Riley, 1984:74).

Burman, (1994a) reviews parenting practices in their historical context and notes that in the nineteenth century, against a backdrop of high infant mortality rates (IMRs), the parental role was one of ensuring religious morality and preparing children for death. The hope of securing a child a place in the afterlife underpinned the need for moral instruction. Medicine later took over religion as a guiding force during the period of Enlightenment, although IMR's were at their highest at the beginning of the twentieth century. A shift from medical to mental hygiene saw the rise of psychology as a science of the mind as opposed to medicine's claim over the body. The period between the 1930's and 1950's was characterised by a move towards children's needs and a focus on the child's natural development. The mothering role was constituted accordingly as a form of pedagogy.

With the post-war period and the economic boom there was a greater focus on the domestic sphere and consumerism. Child care advice also reflected the ethos of the boom years - flexibility rather than prescription (Newson and Newson, 1974). This advice captured the mood of the post war years – a fear of authoritarianism – a concept invoked to explain the rise of facism. In child development terms then, authoritarian parenting practices were no longer admissible and were seen to threaten democracy (Walkerdine and Lucey, 1989).

The link between 'psychic' and 'social struggles' was reflected in the post war psychology in relation to the state nurseries (Riley, 1984). Informed by the work of

Klein, children's primitive impulses - love and aggression- had to be appropriately channelled and dissipated to avoid being carried into adulthood in the form of 'irresponsibility or delinquency'. Riley (1984:1) quotes from a BMJ editorial in 1944 entitled '*War in the Nursery*' (also the title of Riley's book). The article reflected anxieties about the absent mother and the (in)ability of nursery staff as mother substitutes to deal appropriately with infantile aggression.

The fear was not only that certain child rearing practices might be conducive to the authoritarian personality seen to underpin the rise of fascism, but that repressive practices could be seen as a cause of revolutionary fervour, as in the student riots of the sixties (Walkerdine and Lucey, 1989). The project for developmentalists then was to ensure that repression was removed from the authoritarian family and children raised in a new atmosphere of permissiveness and liberal parenting practices.

The pedagogic aspirations of the 1960's made women responsible for their child's cognitive development. Women were charged with the task of providing a secure environment in which their children could explore and play (Tizard, 1991), and became the targets of child rearing advice through a plethora of self help books and magazines (Marshall, 1991). A mother's ability to interact responsively and sensitively with her child, avoiding conflict and confrontation, became the standard by which all mothering was judged. The domestic economy was transformed into a site for educational instruction as women's domestic labour became part of the pedagogy (Walkerdine and Lucey, 1989).

However, normative practices rely on producing a distinction between the 'normal' and the 'abnormal'. In so far as parenting practices deviated from the norm, that of the white bourgeois family, this brought working class and black families under the gaze of welfare agencies (Phoenix, 1987).

Phoenix and Woollett (1991) have criticised the role of psychology in establishing and propagating norms about motherhood based on 'biased' samples of white, middle class mothers observed at home, alone, during the day and outside the context of other adults and siblings, all of which reinforce the mother-child dyad. The use of convenience

samples has served to exclude black and other minority ethnic families. The views and experiences of families who are easy to access may not be typical of those from marginalised groups and those experiencing the effects of economic deprivation. Phoenix (1994), for example, has pointed to some of the difficulties she experienced conducting research interviews with young, black women. Reluctance to take part in the research hinged on a lack of privacy, or a space, in the home where an interview could be conducted, or embarrassment about not being able to offer refreshments because of a lack of money.

Alternatively, when access is gained, judgements about women's adequacy as mothers may fail to theorise the effects of economic factors on parenting practices. Phoenix and Woollett (1991:21) conclude that psychology's narrow focus on what constitutes acceptable maternal practice has not only created a disjuncture between dominant social constructions of motherhood and the reality of women's actual experiences of mothering, but has served to maintain negative constructions of black and working class mothers:

The converse of this omission from psychological studies when the 'normal' is being studied is an over-representation of black and working class families when the pathological is being studied.

I now show how women draw on the discourse of the sensitive mother in their parenting practices, and in particular, their accounts of feeding.

Women's accounts of feeding

Many mothers reported problems with feeding from birth, whereas others spoke of a relatively unproblematic period of feeding followed by a critical incident, such as an illness episode, period of hospitalisation, or an operation, after which feeding never recovered. For some, feeding only became an issue when weaning onto solids. Where children were fed orally, mothers spoke of prolonged mealtimes lasting between five and eight hours a day. For some parents the recommendation of a gastrostomy signalled that the child was 'never going to feed properly' and that 'something was very wrong'.

Given that some parents were coming to terms with their child's diagnosis, they saw gastrostomy feeding as 'another problem on top of everything else', although not all women were opposed to the idea, and many spoke of proactively seeking out a referral.

The meaning of food and feeding and the potential loss of oral feeding as a result of a gastrostomy were common themes. Women reproduced the discourse of the sensitive mother in their accounts of feeding and their concerns that a gastrostomy would not only disrupt oral feeding, but would affect how they related to their child. In interviews with the mothers of Flo, Graham and Cathy, these women constructed feeding as a special or playful time together. These mothers designate feeding as a focus for their relationship with their child, although they do so for different reasons.

Flo's mother

I first met Flo's mother in the outpatient clinic a year before they decided to go ahead with surgery. The child's grandfather accompanied her. At our initial meeting she was undecided about surgery, feeling the surgeon had not really made a good enough case for a gastrostomy and that the decision had been passed back to her. Although the grandfather seemed more convinced of the need for a tube, Flo's mother was not prepared to go ahead with an operation unless she was convinced of the benefits. Twelve months later she came back to the clinic believing a gastrostomy was the best way of managing Flo's feeding.

During the interview I was trying to establish a reason for her initial opposition to the procedure, which she had previously indicated was related to her fear of not being able to feed Flo orally. Flo's mother reported she had changed her mind about the procedure following a children's hospital television programme where a child had a gastrostomy inserted. In this extract, she outlines her reasons for wanting to maintain oral feeding. (Notice how I reproduce the idea of oral feeding as normal feeding in my opening question, which I attempt to correct with the words –'or orally').

G: Cos you said that you were worried about her being able to feed normally, or orally afterwards, and

- M: Yeah, it's, her feeding's like our sort of time together, cos she sits on my lap and I feed her on me lap and she always has something just before she goes up to bed so she sits here with me and has something to eat and a drink before she goes off to sleep, and I didn't really want to lose that with her.
- G: So how, how do you think you might feel if she did sort of stop eating norm, sort of orally?
- M: Um, I wouldn't like it, I'd be very upset if she had to stop eating normally. Cos as well I think it's good for her, just for the taste, everything. It would be one of those things that I'd just have to come to terms with if it does happen.
- G: And you, you sort of said that you know, you sit her on your lap and you have time together, do you think that you could do that with the gastrostomy, how would it change that?
- M: I don't know, I don't know cos sort of most of the time feeding's like, it's not like a playtime, um well she thinks it is, food goes in and she spits it out, but I don't know, cos I really don't know how I'd feed with a gastrostomy anyway but I think sitting her on my lap would be a bit too difficult... Not really thought about that one.
- G: It's something that I've noticed a few parents have started to say, so I just wondered how, how it would impact on your sort of relationship, you know, why would it change, or maybe it wouldn't, or why do you think it might?
- M: Yeah you see if she she's sitting in the chair, to be fed, she wouldn't sit on my lap and do nothing, she'd sit there and be doing something with me, and the feeding was sort of the one thing that we do do like that and always have done. Um I don't know, I hadn't really thought about it, if I couldn't feed her normally as well, it's just one of those things but it's not going to happen so I won't think about it! (laughs). [Flo's mother, 1/2]

The significance of oral feeding is constructed around the notion of a special time together involving physical closeness, with the child sitting on the mother's lap to feed, as well as providing an opportunity for play. The meaning of feeding is conveyed by the phrases 'feeding's like our sort of time together cos she sits on my lap and I feed her on my lap'. This is followed by a further justification about the importance of taste:- 'as well I think it's good for her, just for the taste' (the importance of taste is discussed in chapter 7). She described feeding as a form of play:-'feeding's like, it's not like a play time, um well she thinks it is'. Her concern that feeding would be different with a gastrostomy was alluded to when she stated that feeding was something they did together-'she wouldn't sit on my lap and do nothing, she'd sit there and be doing something with me'. The gastrostomy is constructed as something that would interfere with the notion of togetherness represented as an activity and physical proximity.

The anxiety that the gastrostomy would affect oral feeding, and hence disrupt the 'togetherness' she described during feeding, is signalled in a variety of ways- including laughter, which is often seen as an indicator of psychic tension - hence the use of functions such as, 'I didn't really want to lose that with her', 'I'd be very upset', 'I'd just have to come to terms with it', 'not really thought about that one', 'don't know I hadn't really thought about it', and finally, 'it's just one of those things but it's not going to happen'. The anxiety that the gastrostomy might transform the feeding relationship was fuelled perhaps by an inability to envisage how physical closeness could be maintained around gastrostomy feeding, compounded by a lack of information. For example, some speech therapists advise mothers to massage children's feet while feeding with a gastrostomy tube.

However, underlying this account of feeding as a special time together lies another narrative, that of the 'battle' of feeding and the worry that the child is not getting enough to eat:

- G: Right. And how do you think it [gastrostomy] might sort of impact on the quality of your life then, how might it make things different for you?
- M: It'll probably make things an awful lot easier, there won't be the battle at feeding time, and it will take the worry out of it a lot, if we're out for the day or if we're away, sort of she doesn't want to eat, I can just feed her through the tube. At least I know she's getting it. And also when she's ill she gives up and she just won't eat or drink anything, so at least I know then I won't have a battle with her. [Flo's mother, 1/2]

Here the gastrostomy was constructed as a way of making things easier and alleviating the worry if Flo didn't want to eat, especially during bouts of illness. The use of militaristic metaphors, for example 'battles' or 'wars' to describe the experience of feeding, was also found among other mothers and contrasts with the construction of feeding as a special time:

So a normal feeding time would be like, roughly an hour, just for a small bowl of cereal or whatever with mixed with milk and what not just be about an hour. Because he'll be crying, he'll be coughing, he'll be spluttering in between, I have to be singing to him, make him forget, play with him a little. Sometimes he refuses to eat and we're adamant that he will eat more, so it was like a real war between him and us, because we were adamant that he will eat. [Ahmed's mother, 1/2]

When I go to brush his teeth it's World War III between me and him basically. I have to lie him down on the floor, have him, his head between my knees just to keep him still, cos I'm on my own basically, I brush his teeth that way. You know, and what happens sometimes, he does choke, so he'll cough up and then he obviously, it's a traumatising experience, every time there's anything to do with the mouth it's hypersensitive. [Garry's mother, 1/2]

The advantages are, there's not a big battle any more with feeding because um, he's got an alternative way to feed now, so there's not that 'if you don't eat, you're not going to live' you know, so that's much better for him and um, to get the medicines into him, his fits have improved. [Patrick's mother, 1/1 post surgery]

The use of war terminology also resonates with the war metaphor used by Denise Riley referred to earlier. The idea that the mother-child relationship might be characterised by aggression has become one of the taboos of parenting. Threatening a child ('if you don't eat you're not going to live') as Patrick's mother did; holding Garry's head between her knees to clean his teeth because Garry's mother is on her own and has no one else to help; and insisting that a child eats when playing and cajoling have failed (Ahmed's mother) are all strategies mothers adopted in the management of their children. The accounts women gave suggest that force and coercion exist as part of routine child care - the very thing the developmentalists were keen to avoid. Caring for a child can test a mother; caring for a disabled child can be particularly testing in the absence of adequate resources that might help mothers to parent sensitively. The notion of force within the context of feeding relationships will be expanded on in chapter 8.

However, despite the 'battles' associated with feeding, women spoke of their initial opposition to the suggestion of a gastrostomy. 'Stressful' feeding therefore is not necessarily an indicator of the willingness to proceed towards a surgical solution. It may be the case that women become accustomed to their children's feeding habits and establish different kinds of norms around feeding. Although Flo's mother worried when Flo did not eat, she accepted this was 'normal' for her:

G: So what, how do you sort of feel when she's not eating, what

M: Um, it worries me a bit, but over the years I've come to terms with it, it's just a normal thing with her now. [Flo's mother, 1/2]

In the follow-up interview with Flo's mother, I wanted to explore whether, and in what way, the gastrostomy had impacted on the 'special' feeding time together that she was so concerned to maintain:

- G: Mm, and how have you sort of found that then, cos I know when I spoke to you last time you were sort of saying your mealtimes were quite, in a way, special I think you were saying
- M: Yeah
- G: She used to sit on your lap and
- M: Yeah, yeah. Umm, it's a lot easier because I don't sort of have to feed her and we don't have to cope with the choking, so it is a lot easier, sort of I give her her Nutrini (type of feed) when she's in the chair and then I get her out afterwards and she has a cuddle
- G: Right. So is that the same then, or do you feel that it's quite different compared with before?
- M: No, it's about the same
- G: The same
- M: Yeah, she still has her drink sitting on my lap. [Flo's mother, 2/2]

The concerns expressed in the pre surgery interview about losing the 'special time' were unfounded as she developed alternative strategies for maintaining physical closeness feeding by tube. For example, the mother fed Flo in her chair with the gastrostomy and they shared their special time together after feeding with a drink and a cuddle. The gastrostomy was described as an easier way of feeding as they no longer had 'to cope with the choking'.

Graham's mother

In the pre surgery interview with Graham's mother, she too spoke of the importance of maintaining oral feeding and drew upon a number of discourses to support her decision, despite the concerns expressed by health professionals about the safety of oral feeding. Like Flo's mother, elaborating on the difference between oral and gastrostomy feeding, she constructed feeding as a special time. She indicated the importance of maintaining oral feeding during the day, preferring to use the gastrostomy as a back up for overnight feeds, when Graham was unwell, or for administering medication:

So he has his normal bottle, he loves his bottle, so, and that's, that's our time as well, that's cuddle time. It's like, when he's not been well and I feed him

through the tube, can't have a cuddle cos I'm sitting here with bottles and gear and like and cans of water ready to pour in, so it's that closeness time as well that's at feed time really. And he gets excited. [Graham's mother, 2/2]

Here 'bottle' feeding was constructed as 'normal' and equated with a time for closeness - 'cuddle-time'. The mother reported that Graham loves his bottle and gets excited at the prospect of feeding. When I pressed further to establish why the closeness associated with bottle feeding cannot be replicated with a gastrostomy tube, she suggested the major barrier was the practical limitations of physically managing all the equipment while holding Graham - 'you need about three pairs of hands':

And if I'm holding him, holding the tube, I've got his bottle pouring into the tube, little bottle of water ready to pour into the tube, I can't hold him and, cos I did try it and I ended up knocking the bottle of milk all over the floor, cos I was like, oh my God, and that was at the time when he was being sick as well. [Graham's mother, 2/2]

The use of feeding technologies was described as cumbersome and difficult to physically manage while holding the child - 'my hands are busy'. Whereas the equipment served to 'medicalise' feeding, bottle feeding was constructed as a 'social time', a time for fun. She again constructed bonding around oral feeding:

- M: And um, it's just medical. It's just not the same. Cos when he had his bottle he looks at me and I feed him and it's, it's a social time.
- G: So, so what else is going on when you're feeding him with the bottle between you that's not going on with the tube then?
- M: Um, well, it's just the eye contact and, when he finishes he bites on his bottle and we have a little game there and he'll, he's started to hold his bottle and he'll put his hand on his bottle and he'll put his hand on to my face. Whereas when he's sort of there, because I can't really feed him through the tube when he's in his chair, so when he's on the corner of the settee I'm sitting there and I'm feeding him like this and my hands are busy and he's just sitting there really and that's it. And I can make eye contact with him and I can, but it's more, you've got to concentrate more. It's more natural to feed him with the bottle and I think it's important that I don't, that that carries on, really. So all areas, like the fact that he's learning to hold his bottle, he may never actually be able to hold the weight of a bottle but it's just, it's so hard to describe, if you was to see you'd know what I mean. It's a fun time, play time, social time as well as, but when I'm feeding him through the tube, specially cos I've got another lit, I've got a little one running around, it's just, my hands are busy and I can't, got to concentrate more than I would have to if - he doesn't mind being fed through

the tube, but he does like his bottle. As soon as I walk across the room with a bottle, his bottle in my hand, he knows the difference between his bottle and the baby's bottle. Um, so he, his face lights up and he knows, I couldn't do that to him. [Graham's mother, 2/2]

Graham's mother constructed feeding with a bottle in terms of rapport. This was reinforced by the child's responsiveness to the feeds demonstrated by: recognition of his bottle, visual contact with his mother (although there is eye contact when she tube feeds), game playing involving the bottle, learning to hold his bottle, physically touching his mother and the fact his face lights up at the prospect of feeding. Denying the child his bottle was constructed as a form of deprivation – 'I couldn't do that to him'. However, she also acknowledged that Graham did respond to tube feeding, with grins, for example, at the sensation of feeling full, but added the caveat – 'it's not as fun'. She therefore constructed bottle-feeding as normal, playful, and a time for fun and cuddles. While she recognised that she could 'cuddle' Graham at other times, she designates feeding as the special time where cuddling will take place.

Feeding was also constructed as having a developmental benefit- 'he's learning to hold his bottle'. The developmental benefits associated with feeding are discussed in chapters 7 and 8.

- G: Cos I was going to ask you what do you think he thinks about the tube and
M: Yeah, he doesn't mind it, he doesn't mind being fed through the tube and he was, he will sit there and grin. Um, because obviously he must be getting that full feeling. And when he's not well I think he, it's nice for him as well because he obviously, well he wasn't well last week, he was so much more content once he'd had the feed through the tube. But when I walk across the room with the bottle his face lights up. When I do this with the packets of tube, he's like, not as fun, do you know what I mean? He knows what they are, um, sure he can't tell me he knows but I know by his face he knows he looks down at them and that, so. He doesn't mind, I think it's mainly me probably. But saying that, he loves his bottle. He really does love his bottle. And he loves cuddles. I could cuddle him at other times but I think feed time's a special time you can cuddle. Still my baby. Even though I've got another baby, he's still my baby. [Graham's mother, 2/2]

Again feeding time is reinforced as 'a special time you can cuddle'. The comment that Graham is 'still' her 'baby' (even though Graham is three years old and she has another younger child), demarcates Graham as special (I discuss the idea of prolonged

babyhood in the final chapter). Graham's mother suggested she also benefits from the feeding relationship which she has constructed around feeding and, perhaps, her need to create a special time with the statement –'he doesn't mind, I think it's mainly me probably'. However she also acknowledged that tube feeding might be better for Graham under certain circumstances, when ill for example, suggesting the possibility of redefining tube feeding as a form of caring. It is clear from these examples that women enjoy their relationship with their children, a fact often neglected within discourses of care which construct carers and the cared for in relationships of dependency, rather than inter-dependency (Wendell, 1996).

Children who are already technologised - nasogastric tubes

The previous examples describe women's accounts of oral and gastrostomy feeding. I would now like to explore women's accounts where children's feeding is already technologised, that is they are fed by nasogastric (NG) tube, although, it could be argued that the use of special feeding utensils or 'thickeners' in feeds (to avoid aspiration), also represent examples of feeding technologies.

All families interviewed had some experience of nasogastric feeding. At the time of the interview 14 children had a NG tube, eight of which had been present since birth. The length of time a child had a NG tube ranged from two months to five and a half years¹⁸.

Parents spoke of the difficulties of inserting and managing the nasogastric tube, which children pulled out, necessitating frequent trips to the hospital to have it re-inserted where parents were unable to do this themselves. Despite the difficulties, NG tubes offered parents the reassurance that their child was obtaining adequate nutrition, although some concerns were raised about the perceived negative impact on oral feeding, language development and health (soreness and irritation). The hope that these aspects would improve once the NG tube was removed was expressed.

¹⁸ NG tubes are generally recommended for a period of 6 months.

To some extent the decision to have a gastrostomy was made easier for parents where their child was reliant on a NG tube for feeding. For these parents a gastrostomy was often presented, and accepted, as the 'logical' next stage of feeding, although there were exceptions. Despite having an alternative method of feeding in the form of a NG tube on which Cathy depended for her nutrition, Cathy's mother continued to invest long periods of time feeding her orally.

Cathy's mother

In the interview with Cathy's mother, she also constructs feeding as a playful experience and a time for communication. She indicates her level of investment in maintaining oral feeding by the amount of time she spends coaxing Cathy to eat a few 'dummy fulls' of food:

But I wouldn't, I mean if she did stop feeding orally, please God she never does, I would continue to do that, you know, on the side of things whereas I'm still making her aware of food anyway, you know, you shouldn't be frightened of food and food is here to enjoy whether you're gonna play with it or eat it, I would still do that, because um it's um, I think it's important, it is important. Because I'm gaining a lot by even doing that, I'm gaining a lot, I'm signing to Cathy, the visual contact is there and as long as I'm keeping Cathy's visual contact it's better for her. So apart from the feeding side of things there's a lot of other things involved in this feeding regime type of thing. It's the communication. We communicate on the floor, or, when she's having a bath and that, and I'm signing to Cathy, we sign to Cathy a lot don't we? (to son). So it's keeping Cathy's attention span that little bit longer, and it gets longer and longer and longer as the days go on. [Cathy's mother, 1/2]

Cathy's mother emphasised the dual function of food as something to play with as well as eat. For her, feeding was a time for instruction, or pedagogy, and she constructed this time as an opportunity for 'communication' through signing (because of Cathy's hearing impairment), and learning through exploratory play. Feeding provided an opportunity to maintain visual contact needed for communication. However, the mother acknowledged that communication also took place during other activities, bath-time for example, and not just feeding. Feeding was represented as an activity that develops Cathy's attention span - 'it gets longer and longer and longer as the days go

on'. This construction of attention span draws on a theory of development which is incremental and progressive, 'a gradual linear accumulation' (Urwin, 1986: 258).

The mother's investment in oral feeding is constructed in terms of the amount of hard work and emotional investment involved in establishing a relationship of trust with Cathy through feeding- 'it's been a lot of heartache and you know a lot of tears and a lot of upset'. Again feeding is constructed as a project or task to be worked on. The greater the input the better the return in terms of improvement in Cathy's feeding. The idea that the mother's investments are working toward a goal (possibly one of 'normalisation') is exemplified by the words - 'nobody wants to work so hard to get half-way up the ladder to be knocked back'. The ladder represents the pathway to attainment. 'Half-way up the ladder' suggests progress has been made. The prospect of the child not eating is seen as a reversal of all the mother's efforts described in terms of: 'such a waste of time', 'all your hard work has just gone down the drain' and presumably, a descending of the ladder.

G: How will you feel if she does stop eating, I mean some children do stop eating for reasons we don't really understand.

M: How will I feel? Quite upset really, because it's took me a long time to get where I am now and it's been a lot of heartache and you know a lot of tears and a lot of upset for Cathy, and as I said it's taken a long time to build up the trust between me and Cathy on the feeding side of things and that would be such a waste of time, to think that at the end of it all your hard work has just gone down the drain. I mean, nobody wants that do they, you know, nobody wants to work so hard to get half-way up the ladder to be knocked back. Because I feel at the moment, I feel I'm half-way up the ladder with Cathy, and things are getting that little bit easier as the months go on, feeding is looking a little bit better, she's eating more food, you know, she's tasting more food, she's a bit more willing to taste more food, you know, that makes things a lot easier. I think if she did stop eating that would be a complete knockback, complete knockback and I'd probably wish I'd never had it done. But I can't blame anybody because I'd made the decision. That's why, I think, you know it's important that when you make a decision you're 100% sure that you're ready. I don't think I'd be ready for that, I don't think I'd be ready for that kind of knockback, I think that would really completely shatter me, absolutely shatter me, yeah, I'd be quite disappointed indeed.

G: And is there any other reason apart from that, that you would be disappointed, I mean obviously it's all the hard work you've done and everything

M: Well yeah, I think it would be, if that did happen, I know that nobody can tell me that's not going to happen, and I know that they can't tell me that um she might stop eating for a couple of weeks and she might start again, but if she

doesn't eat again, why does she not eat again, is it because she's had the Nissen, is it because she's had a gastrostomy, and is there really any point in having it done if that's going to be a problem? If it is going to be a problem then there's no point in having it done.

G: So you'd really see it as a quite a negative thing then, what you're saying, you won't, you're not going to view it as a sort of, an outcome of the operation, it's going to

M: I think if she stopped, if Cathy had a gastrostomy and she stopped feeding orally completely, I would find that very negative yeah, that wouldn't look positive in my eyes, that would be very negative, to me that would be saying, well, take it out and put the NG back in, and I'll start again from there. [Cathy's mother, 1/2]

For Cathy's mother, the loss of oral feeding was viewed negatively ('I think if she did stop eating that would be a complete knockback, complete knockback and I'd probably wish I'd never had it done', 'absolutely shatter me', 'I'd be quite disappointed indeed'). Her investment in feeding is signalled by the phrase, 'take it out [the gastrostomy] and put the NG back in, and I'll start again from there'. Here she effects a rhetorical accomplishment which not only communicates her investment in feeding, but also positions her as an active consumer of services exercising free choice. The loss of oral feeding is not necessarily considered a negative outcome in clinical terms, given for some children it would be unsafe to feed orally. However, it does point to the differing perspectives with respect to outcome measures between clinicians and parents and raises questions about whose outcomes count and why?

Garry's mother spoke of the difficulties managing the nasogastric tube that she described as a 'fight' to insert. There is a stark contrast between constructions of feeding as a 'special time' used by the mothers of Flo and Graham (neither of whom were fed by nasogastric tube) and the concerns Garry's mother expressed about the possibility of inflicting harm when inserting the NG tube, resulting in the child being sick or bleeding. The example illustrates the confounding of feeding, caring and harm:

And then when I found that I had to be passing the tube down and when I found the more I had to be passing the tube the more he became sick, and not only that the tube could cause bleeding at the back of the nose, because I found myself not getting it down the very first time, passing the tube down it would hit the back of the nose. [Garry's mother, 2/2]

In the interview with Cathy's mother, she made the distinction between nasogastric and oral feeding. She described how the insertion of a nasogastric tube compromised the relationship of trust built around feeding. The almost 'forceful' aspect of holding Cathy down, and descriptions of her 'screaming' whenever her mother approached the tube, contrast with the playful side of oral feeding which was described as 'nice' and not 'stressful'. Although there was a concern that the gastrostomy might affect Cathy's interest in oral feeding, this was evaluated in the context of not having to insert the NG tube that involved coercion and force:

- M: Obviously when it comes to putting the NG down every week or changing it when she pulls it out, it's a different ballgame altogether, it's a completely different thing. She just doesn't, she doesn't trust me in that sense, the trust isn't there between me and Cathy. It's getting there on the feeding side of things, but still obviously with the NG she's, we're just ..., you know, it's hard work with that, it's hard work. That's why I think with the gastrostomy it would be a lot better because I wouldn't have to keep tampering with Cathy and holding her down, so.
- G: Right. So is it very different when you're trying to feed her with the tube or when you're trying to feed her orally, is it?
- M: Um, it's, no not really, because um, now Cathy's gone on to overnight feeds, so most of Cathy's nutrition is overnight, so she's unaware of having that. So in the morning when she wakes up she comes off because she does have, still has a bolus feed when she comes home from school at half-three, and that's a milk feed and that's like, when you go near the NG that's a big problem because she screams and she really gets upset. Not to the extent where she's vomiting, but she does get upset, and then she also has two juice bottles in the daytime at school, which is the same problem. As soon as you go near the NG it's a problem. That's the only problem really with the NG, it's completely different feeding orally. You've got to really keep Cathy's interest to feed orally, singing to her or constantly praising her that's she's done well on the bit that she's taken.
- G: And how does she react when she's feeding orally then, is she getting distressed or is it a different kind of...
- M: No, she doesn't get distressed when she's feeding orally at all, actually it's quite good, as I say, it's different, it's different to feeding a child who does feed orally, normally, and (brief interruption from other child). Um, yeah you've got to really keep Cathy interested, a lot of interest in, she's got to be playing with food as well, which is good because she's exploring what she's eating as well, and you know it can be fun, it actually is fun for Cathy cos she can, she gets the chance to chuck everything about and she gets it on her hands and at times, and this is also an encouraging part of things, where if she's got her other hand, and she's saying 'no more' she'll do, put her hand to her face, but she's got food on her hand so she's tasting that food, so that's you know you're building up and building up. So feeding Cathy is an experience, it's a nice experience actually, it's not stressful, she will dictate when to stop and when not to, you know

whether she wants more or not, she will make the ... otherwise you just play along. [Cathy's mother, 1/2]

Cathy's mother therefore constructed oral and tube feeding as distinctive in relation to her own role, and her child. The pedagogic aspect of feeding is very apparent and is underpinned by a child-centred discourse. Walkerdine, (1990:35) summarises the principles of the pedagogy as follows: 'Knowledge, understood as concepts, is acquired and produced through the development of an active learner who develops at his own pace by actively incorporating experience'. Cathy's mother constructed oral feeding as an opportunity for exploration, and subsequently, learning - 'she's exploring what she's eating as well, and you know it can be fun'. Exploring through fun is part of the construction of the child. Messy play is encouraged as part of the pedagogy - 'she gets the chance to chuck everything about and she gets it on her hands'.

'Messy play' was very much associated with natural play in the thirties where it began to occupy a 'functional status' in children's development, marking a break with the medical hygienism of previous years where only the child's physical needs were considered (Newson and Newson, 1974). As the authors state: 'at last, the dirty, happy, noisy child could be accepted as a good child' (1974:63).

Oral feeding is cast in terms of a developmental benefit providing Cathy with an opportunity to explore, and have an effect on her world (e.g. she dictates the pace of feeding). This permits a construction of the child in control of her feeding. This child-centred approach to learning has its roots in Piaget, who emphasised the autonomous development of knowledge through 'active' learning and interaction with the environment (Boden, 1979). Going at the child's own pace is very much part of the child-centred pedagogy - 'she will dictate when to stop and when not to'. This contrasts with the more passive overnight tube feeding, delivered by a pump, where the pace of delivery is calibrated by a machine rather than the child. With the overnight tube feeds Cathy is 'unaware' of what is happening as she is asleep. There is an obvious distinction to be had here between oral and overnight tube feeds. The latter is associated with greater passivity, no playtime, fun, or autonomous learning. Nor is

there a role for the mother in promoting development, coaching and coaxing her child to feed.

Unravelling the bond

Having discussed the way some women construct oral feeding as a special time and how they make feeding a central aspect of their relationship with their child, I would now like to return to the issue of bonding and the way women's constructions of oral feeding draw on a biological discourse. Cathy's mother spoke of the special bond enacted through feeding. She therefore designated feeding as the time when bonding takes place:

G: So if, the worst-case scenario is that she stops eating, how would that sort of affect your relationship with her, do you think?

M: Ooh, well that's a tough one, I think it will affect the relationship as far as um, er, I mean we do loads of other things with Cathy that we enjoy together, as me and Cathy, there's a lot of things that we do as a family together with Cathy and we all enjoy it, but I think there's a special bond with me and Cathy that was never there when she was born, because um, because she was taken away, and operations, and blah blah blah, and the bond wasn't really there, so it's like, it'd be a major, I think it'd be a major problem I think on the bonding side of things, because me and Cathy bond quite well on the feeding, when we're feeding you know, it's not when I'm feeding Cathy, it's when we're feeding, we're feeding, I'm not feeding Cathy we're feeding this is the way I look at it, we're doing it, not me, we are. Because I'm trying to teach her to eat herself, so we're doing it, she's not doing it, we're doing it, or I'm not doing it, should I say, Cathy doing it. I'm not doing it it's a partner, the two come side-by-side. [Cathy's mother, 1/2]

Cathy's mother constructed feeding in terms of a joint endeavour, as a form of symbiosis ('we're doing it, she's not doing it, we're doing it, or I'm not doing it, should I say, Cathy's doing it. I'm not doing it, it's a partner, the two come side-by-side'). The boundary between mother and child is blurred as the two become almost merged around feeding. Again the mother constructed the reason for her investment in oral feeding in terms of a compensatory activity for the 'bonding' that failed to take place when Cathy was born. The assumption here is that it is normal practice for mother and child to remain together in order to establish 'an attachment bond'. The emphasis on

‘special bond’ is suggestive of an attachment that was prevented because of a separation at birth.

It is useful to explore the notion of bonding and separation further. Historically it has not always been the practice for mother and child to remain together for the purpose of bonding, reflecting the way different periods support different maternal or childrearing practices (Woodward, 1997). These examples serve to problematise what are considered to be normal feeding practices and their contemporary associations with bonding. Further, Schaffer (1971) suggests that attachments are not dependent on feeding, although feeding may facilitate such attachments. It would appear that there is little evidence to support the view that feeding per se is instrumental to the notion of bonding (Rutter, 1972).

Richards (1979) examines the removal of a child into special care within a cultural and institutional context. He suggests that the uncertainty and lack of communication from professionals over what is happening, exacerbated by complex institutional and hierarchical structures in the organisation of care, contributes to the distress parents experience. Under these circumstances, parents may well feel alienated from the child because of a lack of choice about, and responsibility for, her care. The disjuncture between the idealised image of babies portrayed in baby manuals and the media and the image of a child attached to tubes in an incubator, is stark¹⁹. Child care manuals rarely offer advice on disability which they construct as something undesirable and avoidable providing women follow their advice (Marshall, 1991; Gregory, 1991). The construction of bonding and attachment as a biological process obscures the institutionalised context of care and the conflicts organisational power structures create; although these may serve the purpose of allowing professionals to get on with their work (the task of caring for the child), this may be at the expense of parents getting on with theirs (Richards, 1979).

The discourse of maternal attachment is reproduced by Graham’s mother where she spoke of a ‘strong maternal bond’ to justify her feeding decisions. She constructed

¹⁹ Penelope Leach’s (1988) book incorporates a picture of a baby in an incubator with her smiling and relaxed mother looking over her.

other women who fed their children by tube as lacking a 'maternal bond'. Mothers who 'just' feed through the tube are condemned as lazy, and therefore, indirectly, as bad mothers. Mothers who benefit from the ease and convenience of gastrostomy feeding do so at the expense of (cruelty to) the child:

But, I think you only benefit if, if I was a lazy person, or if I wasn't so attached to Graham, I think I could quite - if I was lazy or I didn't have the bond that I've got with Graham, cos I've got a very strong bond with him, I could see myself just feeding through the tube, that's it, done, and you sit in a corner, shut up, you're fed, and that's it. I could see, I could see how people could do that, because it is just so much easier, if you, you haven't got time to, and it sounds really cruel, doesn't it, I don't mean to sound cruel, but it, I can see how that could happen. And I would never ever want that to happen. [Graham's mother, 2/2]

The use of the 'position call' - 'if I was a lazy person'- serves to position her outside the category of lazy (i.e. bad) mother²⁰. This nicely illustrates the rhetorical function of talk. The mother's statement - 'if I wasn't so attached to Graham'- serves to justify her investment in feeding 'according to the parameters of the moral universe' that she assumes we both inhabit (Chin, 1996:216). As a listener, I hear and understand that she is a 'good mother'.

Mothers often stated that if the only reason for having a gastrostomy was for the convenience of feeding, they would not go ahead with the procedure; rather the child had to benefit. One mother confided that she felt she had 'cheated' her child because feeding with a gastrostomy was so easy. Another mother told me she felt guilty because someone else was now able to feed her son, allowing her to go away for the weekend to visit her own mother. Prior to the operation her son had been totally dependent on her for feeding.

The exploitation of 'guilt' in relation to 'convenience' has not been lost on advertisers. For example, in marketing Betty Crocker cake mix to women in the 1950's it was found that the product did not sell because women felt guilty about the ease and convenience with which they could produce a cake. Focus group research was

²⁰ 'Position Calls', paper presented by Wendy Drewery, Discursive Practice: Narrative and Subjectivity workshop, 1-3 July, 2003. Manchester Metropolitan University.

organised to allow women to free associate their anxiety about the original mix. The convenor of the group concluded that an egg (a gift to the husband) would make the product sell. The extra work involved in 'adding an egg' helped assuage women's guilt by overcoming 'the ease and convenience' barrier (Bernays, 2002).

The ease and convenience of gastrostomy feeding also presented a conceptual barrier for mothers. When women do 'give in' and tube feed, the quality of their mothering is judged by other mothers - a case of women censoring women. By implication a woman who feeds by tube is a bad mother. Again the parallel with breastfeeding should be noted. Women who bottle-feed are constructed as selfish (depriving their child of the natural breast milk and associated benefits), and as feeding at their own convenience rather than meeting the child's needs. As Alldred (1996:146) states: 'selfishness in a mother is supremely deviant; it is antithetical to representations of true motherliness'. The rhetoric of guilt and blame is continued in chapter 11.

Do all women construct their relationships with their child around feeding?

Not all women constructed their relationship with their child around feeding. Carol's parents shared Carol's feeding and also received help from grandparents. The school played a pivotal role in persuading the parents that Carol needed a gastrostomy. There were some disagreements about the best way of managing Carol's feeding, with the school using thickeners in her drinks because of concerns about aspiration. The parents however were unconvinced that aspiration presented a health risk to Carol:

- M: A lot of the problems have been with the school, and I think it's because they worry and they panic.
F: See, I tend to-
M: We tend to think, oh, come on, just get on with it
F: Especially in the morning, when there's five of us to get ready, you know, you've got to get them ready for school, and you do tend to shovel it a bit as well, and
M: And she just eats it
F: Yeah, she'll cough a bit and then back down it goes, you know, I can't. You know, it sounds horrible that way, but you haven't got time to spend an hour.

- It's like when, like our mum's a little slow doing breakfast, but your mum, she stays and it takes forever, because, you know, your mum's very careful with her.
- M: And we just tend to sort of shovel it in
- F: And I'll say to her, 'mum, look, I'll have to do it because she's got to eat it, she's got to go' [Carol's parents, 1/2]

In the above extract, the idea of feeding as a special time is very much subordinate to other family routines and the practicality of ensuring Carol eats breakfast before she goes to school – 'she's got to eat she's got to go', 'but you haven't got time to spend an hour'. The need to get the family ready and out of the house, given both parents work and they have two other children of school age, means there is little time for feeding. The utterance 'and we tend to just shovel it' contrasts with constructions of mealtimes as 'special' reported by other mothers.

Mothers may adapt their feeding techniques in response to a child's abnormal pattern of swallowing. One strategy may involve very rapid feeding. I remember a speech and language therapist for example, presenting a video of a mother feeding her child using such a technique to a group of paediatricians with an interest in feeding disabled children. The clinicians were alarmed and shifted uneasily in their seats (presumably because of concerns about the safety of oral feeding) as the mother was not allowing the child sufficient time to clear each spoonful of food before presenting the next (I discuss this in relation to abjection, the compulsion to look away, in chapter 9). To some extent we all felt some discomfort, but why should this be so? Was it because of the mother's apparent lack of 'sensitivity' in relation to feeding? Was it because she dictated the pace of feeding rather than her child (although she was in fact synchronising her feeding with the child's swallowing)? Was it because the child appeared uncomfortable and was not in control, or was there something about the sight of feeding a disabled child that was disturbing?

The image presented a stark contrast with the idealised cultural image of mothers feeding their children, which is usually represented as enjoyable and fun. However the video did not reflect any of this idealisation; feeding appeared uncomfortable for both mother and child. Although a mother's approach to feeding may not meet the standards of 'sensitive' parenting, in this case it was underpinned by another rationality - that of ensuring the child did not starve (particularly as concerns about the child's weight had

been expressed). Concerns about choking and aspiration (and the potential risk of damage in the longer term) were subordinated to the more immediate need of ensuring the child ate.

The burden of oral feeding was alluded to in the follow-up interview with Carol's parents, where the very obvious relief at not having to spend long periods of time preparing meals and feeding was apparent:

- M: Mmm. You know, whereas I used to think, I tell you, I've got to be honest, whereas I used to think, like if I'm sitting here, if it was a Sunday afternoon, say we'd had our dinner, and 'oh, got to feed Carol now'. You know, it was sort of, neither of us would want to get up and do it and I'd say to him 'well do you want to feed her? Whereas now you just get up and do it and it's done, no problem. Before it was getting really, wasn't it?
- F: Yeah, it does, you know ...
- M: My arm's, my arm's better (laughs)
- F: Yeah, doing that all the time (mimics posture of holding and supporting child)
- M: I used to feed her on my lap
- G: Oh right. Cos it, it took a long time?
- F: Yeah, I used to always hold her on my lap and feed her.
- G: How long did it used to take before then? You're sort of saying now it takes about 10 minutes, how long would it take before?
- M: It could take up to an hour, couldn't it? [Carol's parents, 2/2]

The conflation of feeding and maternal attachment is not reproduced in the above account. In fact the laughing and joking about aching arms seems to perform the function of dissipating the unease, perhaps about the implicit disclosure, that the situation had become untenable with respect to feeding (e.g. Before it was getting really, wasn't it?). Further, for Carol's mother the burden of feeding was such that she refused to take responsibility for the morning feeds prior to surgery, whereas she was happy to do so once the gastrostomy had been inserted because feeding was no longer experienced as a chore.

He [husband] always used to do that [breakfast]. And I wouldn't budge on that, I wouldn't get up, I didn't want to get up and do it, because I couldn't face getting up first thing in the morning and doing all that. So he used to do it, whereas now I'll get up and do this. It's no problem, is it? I just get up and do it. It's fine. [Carol's mother, 2/2]

Conclusion

In this chapter I have demonstrated how scientific discourses of mothering serve to reinforce the natural, and apparently universal, aspects of the mothering role. The discourse of maternal sensitivity positions women as feeders and nurturers (closer to nature) and constructs their domestic work as a form of pedagogy through the incorporation of play into their domestic routines. Walkerdine and Lucey (1989:82) suggest learning through play became an educational doctrine in the 1930's and was popularised by the Plowden report in the 1960's. Piaget saw play as the basis for the development of children's intellect. Learning was about fun and mothers were charged with the task of aiding their children's educational development by providing the right environment. Play and learning therefore became inextricably linked. The inscription of play in contemporary professional, developmental and children's rights discourses is also apparent (see for example, the United Nations Convention on the Rights of the Child –Article 31, cited in the report by the National Playing Fields Association, 2000).

It is the discursive practice of play which women reproduce in their accounts of feeding as a special time. This was evident in Cathy's mother's constructions of feeding and play as a form of learning and an indicator of her child's developmental progress. Not surprisingly, given many of the women interviewed had attended feeding clinics and received advice about their children's feeding, their accounts incorporated professional discourses which they in turn incorporated into their own practices. This was particularly apparent with Cathy's mother and her constructions of food as something to eat and play with, her talk of 'messy play' and her constant praising and reinforcements (underpinned by a behaviourist discourse). These are examples of what Rose (1985) has termed the 'psy-complex', which I elaborate in the next chapter.

Why is it then that women come to participate in the surveillance of their mothering?

In chapter 2 I introduced the concept of governmentality which refers to Foucault's idea of the 'disciplinary society - a society in which individuals are organised through various expert knowledges'(Gilleard and Higgs, 2000:101). Science is inextricably bound up with notions of normalisation. Moreover, norms of mothering, child development and behaviour are increasingly popularised by the media, women's

magazines and child care manuals (Marshall, 1991). Urwin (1985:166) suggests regulatory practices 'give specific content' to women's 'desires, aspirations and daily work and by occluding alternative options'. These regulatory practices are internalised through the idea of the 'panoptican' and translated into systems of 'self-governance' (Gilleard and Higgs, 2000:102), such that:

There is no need for arms, physical violence, material constraints. Just a gaze. An inspecting gaze, a gaze which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself. (Foucault, 1980:155)

Women perform an instrumental role in producing the normal individual, not through coercion, but through their active engagement (Rose, 1989:130). As such: 'the images of normality generated by expertise' serve as a means by which individuals 'normalise and evaluate their lives, their conduct, and those of their children' (1989:130). Although the technologies of the self appear as rational, free choices, they are choices increasingly 'sponsored by governments' (Gilleard and Higgs, 2000:102).

I explore these themes further in relation to the contradictory and dilemmatic aspects of feeding discourses which I situate in the wider context of child development, disability and children's rights in the next chapter.

7. Developmental practices and children's rights

'If he hasn't got the co-ordination with his tongue to move food around in his mouth correctly, what's his tongue going to be like for language development?' [Edward's mother]

Introduction

The above comment illustrates one mother's concern about her child's feeding ability and the relationship with language skills. In this chapter I am going to examine women's accounts of oral feeding in relation to developmental practices. Richter (1994) suggests that women hold tacit theories of child development which strongly reflect cultural images of the ideal child. In Anglo-US culture the agentic, self-contained model of subjectivity is privileged, reflecting the core cultural values of autonomy and independence. Indeed proponents of theories of poverty as a culture blame poverty on the habits and behaviour of the poor: poverty and dependency are transmitted by parents 'who do not inculcate in their children the traits of autonomy, independence and ambition' (Richter, 1994:32 quoting McLoyd, 1990). Personal responsibility for economic self-sufficiency is very much an ethos of the Labour government's Third Way and has its roots in the Victorian era (Shuttleworth, 1994; Scambler, 2002).

I explore how constructions of the idealised child, and the cultural values of autonomy, independence and self-reliance inform women's parenting practices in relation to feeding and highlight how women's constructions of feeding form part of this project towards cultivating independence.

The child first and always

In the hospital where I conducted the study, the logo firmly enshrined the notion of children's rights with the caption, 'the child first and always'. This is a far cry from the old adage, 'children should be seen and not heard', suggesting the privileging of children's rights is a recent phenomenon informing the social construction of the

contemporary modern child. Developmental psychology, as evolved within a Euro-US context, assumes an individualist framework of development where the child is seen to progress along a linear trajectory, often conceptualised in terms of a fixed series of stages which are considered to be universal (Burman, 2001).

Lee (2001:113) notes the way children have been constituted as incomplete adults and draws a similar parallel with women who are also constructed as lacking completeness, morally and intellectually, compared with men. Constructions of the child rehearse the nature-nurture couplet whereby children's 'incompleteness' needs to be supplemented through culture – 'an incomplete nature and completing culture'. Similarly, in raising the question of whether children grow or are made, (Burman, 1994a:49) points to the way childhood has been differently constituted in accordance with specific historical eras and how different models of development have informed childhood practices, thereby contesting the view of child development as universal and natural. Ideologies of child rearing in Western culture in the last sixty years have moved from a concern with hygiene and discipline to one of children's emotional development (Newson and Newson, 1974). Theoretical claims about the universality of child development, then, are based on locally collected data, usually from the West, which has implications for how we generalise findings and think about childhood in other cultures.

Childhood experiences may vary as a function of geographical and historical location, famine, poverty, disease and war. Prior to the industrial revolution children were viewed as miniature adults and were not afforded a unique or protected status as they are in today's Western industrial democracies (Aries, 1962). Contemporary images of 'child soldiers' in Sierra Leone, child workers and children living with HIV and AIDs in Africa, for example, transgress common constructions of childhood as a time of innocence and dependency (Burman, 1994b). To proclaim the right to a childhood as we perceive it here in the West is to view childhood from a particular vantage, and advantaged, point.

Lee (2001:27) situates the construction of children as dependent, vulnerable and different from adults, and thus requiring protection through legislation, in its historical context. Lee argues that the separation of children from mainstream society relates to

the rise of the nation state. As states began to compete in economic and militaristic terms a new relationship was forged between rulers and ruled. The success of the state depended on its people and as such they became the focus of regulation through education and health. With modernisation came practices which regulated citizens as their management became more organised, rationalised and disciplined. The need to separate children to secure their development for the future gave rise to a host of experts and practices. Accordingly children became the sites of investment within the developing nation state, which guaranteed their unique status as dependent (Lee, 2001 quoting Donzelot, 1979). That children are treated as different from adults is apparent in the United Nations declaration on the Rights of the Child, reflecting the view that children need a different kind of protection to that afforded by existing human rights' conventions (Lee, 2001). In its extreme, such rights are extended to the unborn and militate against those of mothers. I discuss the issue of conflicting rights in the final chapter.

Mothering as a pedagogy

So far I have suggested that the mothering role has changed over the years from 'medical hygienism' to one of 'greater permissiveness' in relation to child-rearing practices (Newson and Newson, 1974). I have also discussed how the discourse of the sensitive mother serves as part of the regulatory apparatus in establishing normative practices vis-à-vis the mothering role.

In chapter 6 I discussed how ideas drawn from psychoanalysis have been incorporated into normative practices of 'good mothering' which serve to regulate women and family life (Urwin, 1986). The quality of interaction within the mother-child dyad has been the focus for many aspects of a child's development, not only in terms of feeding and the feeding relationship, but also in terms of language, cognition and behaviour. The privileging of the dyadic relationship, despite changes in family constitution, places the onus of responsibility for children's development, education and welfare on women in their role as mothers.

Walkerdine and Lucey (1989:29) suggest that women's domestic work has been transformed into a pedagogy that forms the basis of children's cognitive development. Underlying this pedagogy lies an ideology designed to produce the 'free, liberal, rational thinkers' necessary to participate in a democratic society- 'successful parenting rests on creating an illusion of autonomy'. Mothers are charged with the responsibility for ensuring their children experience a sense of personal liberation by avoiding power struggles and overt regulation, which are perceived to threaten the child's sense of autonomy. Whereas middle class women are seen to (albeit unwittingly) fulfil this function, black and working class mother's child rearing practices are pathologised as 'insensitive' and become the focus for deprivation theories. Working and middle class mothers, then, are 'differently but oppressively regulated' through scientific practices that establish norms in relation to child rearing and mothering.

Walkerdine (1984:153) suggests a 'pedagogy of liberation' also underpins much of contemporary educational practice. Discipline has shifted from overt to covert regulation, where children are imbued with a sense of autonomy and control as the power traditionally invested in the teacher becomes diffused through the mastery of reason. Conflict is displaced in favour of rational argument – power is seen to reside in the winning of the argument rather than hierarchy and overt regulation (Walkerdine, 1988:210).

Science then plays a pivotal role in establishing normative practices that become naturalised as truths. Such disciplinary regimes inform discourses of mothering which serve to regulate women. Not only is a woman's effectiveness as a mother under scrutiny, but her effectiveness as a pedagogue is also questioned, such that a mother whose children fail to attend school is sent to prison. In the case of 'Mrs Amos' in the UK for example (Gillan, 2002), truancy was constructed in terms of inadequate parenting. The responsibility for school attendance was levelled at the mother rather than the system of education, or society. This approach fails to address the underlying reason(s) why children truant. There is a parallel with the way Victorian women who did not conform were incarcerated. A woman who fails to perform her duty as an educator is similarly punished today. In terms of policy, it is probably easier to castigate and incarcerate women than deal with the root causes of truancy and social

exclusion. The fear of an alienated 'underclass' informs the communitarian policies of the current Labour Party, which promotes policies permitting the imprisonment of parents for failing to carry out their obligations and curfews placed on aberrant youth (Dalley, 1996:159).

The right to experience: taste and pleasure

Parents often gave the pleasure of eating as a reason for wanting their child to feed orally. Experience with different tastes and textures was seen as important. As one mother said:

Oral feeding is pleasurable for him. If he has absolutely nothing else, at least he can taste, he would get pleasure. Whether he did or not I don't know, he never communicated it. But different tastes, sour, sweet...pleasurable [Exit interview, clinical evaluation]

Parents would often project their own enjoyment of feeding on to their child. For example, in the account given above, a contradiction exists between the statement that feeding is pleasurable for the child, and the mother's admission that she does not actually know this to be the case as the child has never verbally communicated his enjoyment. Rather, it is assumed. Similarly, for Paul's mother discontinuing oral feeding was tantamount to depriving him of the 'only thing that motivates him in life':

And I mean certainly we've been advised the best thing you could do with Paul is to stop oral feeding him altogether and just give him the tube. But I have an issue with that, well I have three issues with that, one is that Paul will take it, he loves his food and I think if you turned round and said he couldn't have food again he would even get to the point of turning his face to the wall, and saying well why should I bother, because the only thing that really motivates him in life is around, well not the only thing but it's certainly the, you know if you had put it in weighting it must be 40% and other things 5/10% elsewhere, or perhaps 20% television. [Paul's mother, 2/2]

The prospect of not being able to eat was such that the mother suggested the child would give up on life – 'he would even get to the point of turning his face to the wall, and saying well why should I bother'.

In the account given by Graham's mother, she emphasised the importance of maintaining oral feeding despite the risk of aspiration. Special treats, which ultimately may be harmful, were justified in terms of a normalising discourse: 'because our normal thing is to eat', and the association between pleasure and feeding. Here the mother is balancing the risk of aspiration against a child's right to enjoyment, happiness and good quality of life, which she constructs through the medium of oral feeding, and herself as the guardian of Graham's happiness. These constructions serve to marginalise discourses of risk. Denying Graham the 'things he loves' is associated with 'wickedness' and subsequently bad mothering. Graham's mother fulfills the requirements of sensitive mothering through oral feeding and thereby meets the child's needs, demonstrating the way mothering has come to be defined in relation to children's needs (Urwin, 1985):

You know the difference between the bottles, if you give him a bottle of just plain soya milk and a bottle of soya milk with all his stuff in [thickeners and high calories substances] which he has to have, he drinks the soya milk just by itself so nice. He really does enjoy it. So I do tend to, every now and again give him a bottle without all this stuff, which I know I shouldn't, but he enjoys it more. So I'm just really hoping I'll be able to have the best of both. Get him to have everything he needs during the night and get him to have nice bits and pieces during the day to make his quality of life as best I can, really. That's my role, I'm his mum and I want him to be as happy as I can make him. I mean, he loves, um I get special ice-cream for him that hasn't got like, milk in and that, and he loves that, he really does love that, and I know, I know things that go, I know anything he has he does aspirate, but I think it's really wicked just to stop everything. Do you understand what I mean, I don't know, it doesn't seem right. But I suppose it's because our normal thing is to eat, isn't it, we eat and drink and if we want something nice we'll have something nice and I think that's a shame to stop him having something nice [Graham's mother, 1/2]

Similarly, Edward's mother constructed oral feeding in terms of 'pleasure' - a source of 'joy and comfort'. Not being able to eat was constructed as something the child would 'miss out' on:

It's a great source of anxiety that Edward may never speak properly and may never feed properly. Um, food is a great source of joy and comfort and social, er pleasure. From that aspect alone it's something that he'll miss out on. [Edward's mother, 1/1, post surgery]

However, the desire to experiment with tastes and textures was not always replicated by other parents:

- F: Because if I give him anything with a lump in he'll just be sick, he'll just start gagging.
- M: If you gave him like, sometimes we'll give him some, if we were drinking, fizzy orange or something like that and you think oh well I'll just try that.
- F: Just give him a taste of it, just another example of something.
- M: Suddenly it's just, you think, you like to try him to give him some different flavours and things, but it just, he punishes you for it. He wants to take it, he pulls the cup to him.
- F: Yeah he does, he wants to and then the next minute you've got it returned.
[Duncan's parents, 1/1, pre surgery]

In their child care manual, Dr's Spock and Rothenberg (1992:366) advise parents to 'let a child's natural appetite come to the surface so that she wants to eat'. However in Duncan's case, even though he indicates he wants something (he pulls the cup to him), this invariably results in him being sick. Duncan is unable to cope with different flavours and responds to his parents' attempts at experimentation by 'punishing' them ('you've got it returned') which contrasts with other women's accounts of feeding as a special and rewarding time. Dr Spock talks about children having inborn mechanisms which let them know how much, and which types of, food they need to grow. Children with a condition known as Noonan syndrome however, neither seem to experience hunger nor to associate food and hunger²¹. They therefore have no natural appetite. Similarly, in Duncan's case his 'natural' state is not to tolerate different tastes and textures.

The difficulty of denying children food when they indicated they wanted to eat was mentioned by parents following the insertion of a gastrostomy. For example one mother spoke of the way a child 'screamed' to be fed certain kinds of food. Another mother spoke of how her son wanted the 'Sunday roast', not tube feeds. Meals in front of children were difficult scenarios for families, although they usually coped by feeding the child by tube first to satiate hunger before the rest of the family ate.

²¹ Noonan Syndrome. <http://rhpc205.uio.no/sss/English/Disorder/ED_noon.htm> [Accessed 7-12-99]

The Guardians of Development: autonomous children

'The whole of her enjoyment, occupation and learning is in your hands' [Leach, 1988:453]

It might be worth exploring in greater detail what it is women are trying to achieve by exposing their children to different tastes and food textures. I suggest the reason for parental emphasis on the importance of varying their children's diet with a range of tastes and textures is that they are creating a learning environment for their child in accordance with a child-centred discourse. Given children are unable to explore in the conventional sense because of their restricted mobility, and visual and hearing impairments, for example, and they may not be able to reach, grasp or crawl, parents are faced with the challenge of providing an alternative learning environment. In the same way parents attempt to create stimulating environments with objects, educational toys, books etc designed to facilitate their children's development, the mouth, experiences with tastes and textures, and mealtimes are reframed as a learning environment for the disabled child.

Feeding behaviour is often taken as an indication of a child's developmental progress. For example, weaning at 4-6 months, and the use of utensils, knives and forks, rather than fingers or a spoon, are viewed in developmental terms according to age appropriateness. The Paediatric Evaluation of Disability Inventory (Haley et al., 1992), measures functional ability in disabled children and has three sections devoted to feeding in the self-care domain. These are food textures, use of utensils and use of drinking containers. Within the food textures domain there are four levels of ability (assumed rather than stated) measuring feeding skills ranging from the most elementary (eats pureed/blended/strained foods) to a more advanced stage (eats all textures of table food). Implicit in the scale is an expected, logical progression towards the attainment of skills and is strongly influenced by a stage theory of development such as that put forward by Piaget.

Although the universality of Piaget's theories has been questioned (Dasen, 1998), his work continues to be highly influential. Piaget advocated a stage model of cognitive

development whereby learning is characterised as a series of stages or building blocks which gradually unfold in a predetermined order in a complex, dialectical relationship with the environment (Boden, 1979). Learning is viewed as natural, sequential and invariant, such that a child cannot learn to walk without having attained other sensorimotor skills like a sense of balance. Children are expected to have reached particular stages by a certain age. Deviations from the norm can be construed as either regressive or precocious (Wallander and Varni, 1998).

In Piagetian terms, sensorimotor experience forms one of the basic building blocks of intelligence. As Boden (1979:30) states:

Intelligence is mediated by the baby's sensory and motor system's, which she uses to change and learn from her environment in increasingly purposeful ways. And by adapting to her environment she creates her world, for a baby sucking is constructing a world of suckable things (not merely finding things in the world that she sucks).

Sucking is therefore constituted as a form of intelligence. Eating and drinking, and in particular experience with different textures, also constitute a form of sensorimotor activity. Boden (1979:47) quotes Piaget:

Sensorimotor activity implies that activities are assimilated and accommodated, and this is the case with any child that lives, since it has to eat and drink (involving assimilation and accommodation-one drinks and eats very different things, and adjusts the movements according to the substance), and since it has perceptual activity (movements of the eyes and the head, if that is possible), also follows the same patterns of co-ordination.

Constructed in these terms oral feeding not only indicates normal development, but a building block on the pathway to independence. This is not to say that parents are experts on Piaget and talk about the importance of oral feeding in terms of sensorimotor development; rather I am trying to pinpoint the origins of the developmental discourses in parental accounts. Rose (1985), for example, has spoken of the 'psy-complex', the popularisation of psychological discourse, once the domain of experts but increasingly accessible to lay people through child-care manuals, the media and self-help books. The uptake of developmental discourses, as reflected in parental talk, is an example of the 'psy-complex'. Parental emphasis on the importance of children's experience with

different tastes and textures has its roots in the discourse of the developmentalists. Further, a good appetite is also taken as evidence of a child having attained a 'normal stage of healthy development towards independence' (Newson and Newson, 1970:232 quoting Apley and Mackeith, 1962). Willingness to eat varied foods of different tastes and textures, and the ability to indicate a preference with respect to food, are viewed as parts of this move towards independence and maturity. Children who eat the same food as adults are 'growing up'.

Paul's mother equates variety with an enjoyable life, (hence the old adage variety is the spice of life). Paul's interest in different types of foods not only signals a healthy appetite, and good health, but is taken as an indication of 'normal' development. The idealised image of the autonomous child informs the mother's account of her child's feeding experiences:

Because he is dying to get different foods at the moment, I mean his mouth drools when he sees some of the food that [his sister] gets and it's only basic food that you or I may have but he can't handle. You know if I can start giving him a bit of a variety of food I think he'd enjoy life more as well. [Paul's mother, 1/2]

For Nicki's mother, the use of a fork is synonymous with being grown up ('a grown up fork'). Similarly, the interest in adult food (despite the fact the child only tastes, rather than eats it), particularly 'strong savoury food', which contrasts with the milk feeds and purees Nicki usually eats (and the association with baby food), is indicative of a child maturing and becoming independent:

When we were out in the café, when we were out for Sunday lunch, we were sitting round the table altogether. She just loves tasting absolutely everything that we have, whether it's garlic, whether it's curry, or whether it's, really strong savoury food, off a fork, off a grown-up fork. [Nicki's mother, 2/2]

Similarly, Graham's mother expressed her concern that in becoming reliant on the gastrostomy, Graham would 'lose his sucking skills', the logic being that he wasn't born with the skills. The skills are something he has achieved for himself (with the help of his mother) and represent an example of autonomous learning:

Plus um I don't want him to lose his sucking skills, I don't want him to eat his, he doesn't chew but I don't want him to lose them skills that he's, he's taken so long to sort of learn really. I mean he wasn't born with them skills, it was very hard to get him to have anything, um cos I did say to the consultant about that, I don't want him to lose what he's got. [Graham's mother, 1/2]

There is a tension therefore with popular images of children, particularly disabled children, as passive and dependent, and the parental task of making them active and autonomous. Again oral feeding with its associations with autonomous and natural child development signals normal, healthy development. Conversely, tube feeding, with its association with passive feeding (see the example of Cathy in the previous chapter), can symbolise a regression. One mother commented on her reaction to the suggestion of a gastrostomy as a 'shock'. She felt it was a 'retrograde step' because she had assumed feeding was improving.

Similarly, parents may find the idea of substituting textured food, with formula tube feeds, as regressive. Here parents are drawing on a theory of development constructed as linear, sequential and moving forwards not backwards. Hence 'losing skills' is constructed as part of that regression. Since a mother's job is to promote development we can see why there is an investment in oral feeding. A failure to maintain or promote skills is seen as compromising a child's development and autonomy, and questions a woman's parenting skills.

In the next extract, oral feeding is constituted as part of a developmental discourse. Again the importance of autonomy and self-reliance is emphasised by Paul's mother. She contrasts oral feeding, as something he can do by himself, with other aspects of his life where he is dependent on others. Although he cannot self-feed (i.e. put the food in his mouth), 'once it's in his mouth he's in control'. Further evidence that oral feeding is improving (in line with conventional developmental trajectories) is Paul's ability to 'move the food around in his mouth'. Given the mother's perception that Paul can eat, enjoys eating, and chooses to eat, medical advice not to feed orally may well be disregarded. Further, as Paul's mother accepted that Paul was going to be underweight ('it's in his nature, he's never going to be a porker'), using the gastrostomy for the express purpose of weight-gain is not a major priority:

Yes, I mean Paul enjoys that, I think it's good for him to experience that sort of social occasion, and you know a lot of people their social life revolves around them going out for meals or whatever, and for Paul he enjoys it why not do it. I'd always encouraged him to be interested in food because actually you know he's always going to be underweight, he's always going to be a bit skinny even if he gets more food and it's the nature of his spasm things, he's got so much energy, he's never going to be a porker. So if he likes food and he can do that then why not keep it going. I think the worst thing would be to make him uninterested in food. Now at the moment you could still say he's a bit obsessed by it, but actually I think that's just, it's the one thing he can do, everything else he's dependent on other people doing x, y, z, whereas he can actually, you know he can get it in his mouth, OK you have to give it to him in his mouth, but once it's in his mouth he's in control then, and he enjoys it so our view is we will continue doing that. Now obviously if you got to the problem that he couldn't eat, for whatever reason, then that's different. But actually what we're finding at the moment is that with his gradually improved head control, his ability to move the food around in his mouth and actually eat I think is improving. [Paul's mother, 2/2]

Cultivating independence in children is considered an important aspect of Western child-rearing practices, for example, self-feeding skills, potty training, and dressing. When women disregard medical advice to use the gastrostomy in place of oral feeding, it is because they are crafting developmental environments for their children in keeping with ideologies of child-centredness and sensitive mothering. Their child is being 'cultivated into maturity' (Nsamenang Bame, 1996) and subsequently, independence.

However, as Dwivedi (2000) suggests, the construction of the child as autonomous is consonant with Western ideological representations of the individual. In Eastern cultures, child-rearing practices reflect an alternative vision of self characterised by dependability and relatedness. The emphasis is less on individuality and autonomy as on 'prolonged babyhood' (this is taken up in the final chapter). Nsamenang (1996:65) comments on the way different ideologies constitute subjectivity:

An independent script that informs a Euro-centric psychology constitutes a different 'psychological frame of reference' from that of an interdependent script that ordains psychological functioning in non-Western societies.

What is considered developmentally normative then needs to be taken in its socio-historical and cultural context. Richter (1994:33) quotes Ogbu (1981): 'child rearing techniques serve only as a mechanism for inculcating and acquiring certain culturally

defined instrumental competencies'. The role of ideology and how this permeates child-rearing practices offering alternative constructions of the child needs to be theorised.

Eating and talking

A common reason parents gave for wanting to orally feed younger children, regardless of whether feeding was considered safe or not, was a belief that the same sort of (motor) skills were needed for language as for feeding. Underpinning this was a belief that the child would possess the capacity to develop language skills at some point in the future:

G: Has that been a particular issue for you then, the oral feeding?

M: Very much so, very much so. Because, and it's two, it's two-edged or two-sided, because there's not only the aspect of will Edward ever feed normally or drink normally, how is his speech going to be, speech and language going to be developed? Because if as they tell us the same skills are used for feeding as for speaking then if he hasn't got the co-ordination with his tongue to move food around in his mouth correctly, what's his tongue going to be like for language development? So yes, we're very concerned about his speech and language development. [Edward's mother, 2/2]

Edward's mother constructed a link between the skills needed for feeding and language development, a relationship that is very much contested in medical circles. Her concern about his speech was such that she privately hired a speech and language therapist. Many families would not be able to afford this and it would fall to the mother to develop these skills. Edward's mother stressed that she would rather Edward spoke than fed 'normally' if she had to make a choice (a forced choice), despite her previous comment that 'food is a great source of joy and comfort'.

Nicki's mother forged a similar link between oral feeding and speaking, her justification for maintaining oral feeding, although she added the caveat that perhaps she was trying to achieve too much:

And I want to persist on that (oral feeding) because I know that it's important for any kind of, possible language learning as well which is really important to get her kind of moving and swallowing and using her mouth, you know. Maybe I'm trying to achieve too much, I sometimes feel, God, what would I give up, it's hard to balance out what you're trying to do really. [Nicki's mother, 2/2]

The emphasis on the emergence of language through activity underpins the desire to maintain oral feeding (Burman, 1994a:112). The very medical terminology used to describe children with developmental disabilities (i.e. as 'developmentally delayed') is perhaps misleading as it is suggestive of a latent capacity within the child waiting to emerge under the right conditions and is informed by a stage theory of development. For example, Spock and Rothenberg (1992:313) advise in their child care manual: 'Naturally, the child who is severely retarded, who can't sit up, for instance, until 2, will be really delayed in talking' .

This advice tends to suggest that the child will talk but at a much later stage. In the face of an uncertain developmental trajectory therefore, parents may continue to assume their child will develop along the same lines as other children and continue to parent along those lines. Disability therefore may be constructed as temporary:

And I hope he's going to, like, you know outgrow it, that's why, I'm hoping that it'll be for now, then in the next couple of years he should be eating, you know, as his condition improves, muscular condition improves, his general, cos he is improving a lot. [Ahmed's mother, 2/2]

Parental hopes that their child will 'talk' is underpinned not only by a strong normalising discourse, but an expectation that with the right kind of input or therapy, the child will learn to speak. As Walkerdine and Lucey (1989:62) state, not only are women responsible for ensuring their child's mental health, they are also responsible for their children's educational achievement by teaching and developing their language. A failure to maintain feeding skills, and therefore indirectly the apparatus needed for language, is constructed as depriving the child of her right to speak, and ultimately to participate, positioning women as the lynch-pin between child and the community. The notion of self-reliance and active participation are encapsulated in the United Nations Convention on the Rights of the Child (point 1, Article 23):

States Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community²².

²² Unicef. Convention on the Rights of the Child, Available:< www.unicef.org/crc/crc/htm > [Accessed: October 8, 2003]

A failure to maintain oral feeding skills and, subsequently, language skills is constructed as the denial of the right of the child to achieve her potentiality. I discuss children's participation and involvement next.

Count me in – the right to be included and participate

Parental accounts emphasised the role of feeding in family life and social occasions. Constructions of tube feeding as an exclusionary practice were underpinned by a discourse of rights, that is, the right of the child to be included and participate fully in all aspects of life.

Like the girls, they'll sit down and they'll have a biscuit and a drink, well Graham he doesn't have a biscuit cos he can't, but he'll, he will have his drink there. He doesn't touch it but he will have his drink there, and he can, like, I'll hold it to his mouth and he doesn't want it, he doesn't want it. But I think that's, I do think that's very important. Even if it's one or two sips of a drink, I think, just for the family unit really, so he's not sort of pushed to one side, oh that's Graham in the corner, sort of thing, he must be involved. Like, we go out in the garden, he comes out the garden with us. Do you know what I mean, it's just, just because he can't get out there himself doesn't mean to say he's not entitled to, it's just, I think it's very important. I feel that's very important. [Graham's mother, 1/2]

In the above account, Graham's mother constructed the right to be included in family activities as an entitlement (just because he can't get out there himself doesn't mean to say he's not entitled). Even though the child was not able to participate in the actual meal, his mother emphasised the importance of including Graham in the 'family unit'. Graham's mother therefore constructed tube feeding as synonymous with exclusion - 'pushed to one side', 'in the corner'. She drew on these constructions to justify her decision to maintain oral feeding in social arenas with peers and family, preferring to use the tube as a back-up, or for overnight feeding:

Cos at least then if we go out, if we go out for something to eat, even though he can't eat the food that's there he can still have a drink with us, or at dinner time he can still have a little bit to eat or drink with us. [Graham's mother 1/2]

Similarly, Paul's mother accounted for her persistence with oral feeding, contrary to medical advice, not only in terms of the child's enjoyment (Paul loves food), but in

relation to discourses of inclusion constructed around the family 'meal environment'. Eating was constructed as part of normal life- 'we all eat three or four times a day' (despite that for many people, and for the children in this study, this is clearly not the case) although she acknowledged that life wasn't normal for Paul:

I think it's important for him to feel part of as normal life as they can, I mean life isn't normal for him, I know that. But on the other hand to exclude him from a meal environment, you know given we all eat three/four times a day, and all those coffees and teas and whatever, I think he would feel excluded. Because at the moment, yes he doesn't have the same food as us but he will try bits of our food and he'll enjoy the meal experience with us sitting there and we'll chat to him and he chats to us, and you know there's an involvement there which I think if he was just sitting there with a tube and watching us stuffing our faces and he couldn't eat, I think he would feel very excluded. [Paul's mother, 1/2]

Again gastrostomy feeding is represented as exclusionary and a barrier to involvement defined as enjoyment of 'the meal experience', communication – 'we'll chat to him and he'll chat to us', and the sharing of food- 'he will try bits of our food' (as we have seen, eating adult food is constructed as developmentally normative). The construction of mealtimes as an opportunity for conversation however, masks the different classed and raced locations of food and eating.

Contrary to the previous account, Joshi's parents spoke of how the gastrostomy facilitated inclusion in the family meal by virtue of the overnight feed which is the main source of his nutrition. The benefits of gastrostomy were defined in terms of 'less worry' about feeding as the tube took the 'pressure off', particularly in the mornings, when they had the reassurance of knowing Joshi wasn't hungry as he had been fed by tube overnight. This gave Joshi's mother time to prepare the other children for school. Joshi then had a 'normal breakfast, dinner and tea'. The mother emphasised the importance of including Joshi as part of the family which she also constructed around mealtimes, although she was unclear about what constituted a 'proper mealtime':

M: He has the feed over night so we don't have to worry so much about the amount of fluid that he has during the day because he's having 400 mls roughly, he doesn't always have the same amount, but roughly 400 mls overnight, so we don't have to worry now, and also we don't have to worry first thing in the morning as soon as he gets up he's got to have some breakfast because he's hungry, so now we know he's had that milk over night. So that's a little bit

easier in the morning now, although I do sometimes offer him some he's never that hungry when he wakes up in the morning so it gives you time to bath and get everyone else off to school and then sort of concentrate on him really when they've gone off. So it takes the pressure off of sort of those types of things really. So he really just has a breakfast, dinner and tea and you know we try and sort of like, especially at tea time he'll sit up the table with me on my lap, or he'll be around us so we try and have a normal breakfast, dinner and tea as much as you can. So he's feeding at the same time as everyone else I suppose, to make him ...

G: Did you do that before [surgery]?

M: Well what did we do before? I can't remember. I suppose we didn't perhaps so much did we because he was having, we weren't really tube feeding him over night were we in the end? Nasogastric tube feeds.

F: Where are we?

M: Well you know now he has a pump overnight doesn't he so we don't have to worry so much do we?

F: No, about feeding him, what like he'll be feeding, does he sit down with us?

M: Do we have proper mealtimes?

F: Yeah.

M: Yeah well we've always tried to, you know he is part of the family and he does what everyone else does really, so there's always been a great emphasis on that hasn't there, that he's just part of the whole family. [Joshi's parents, 1/1, post surgery]

In contrast to the notion of the family meal as a social occasion, John's parents, designated the school meal as the stimulating environment: 'there's lots going on and to look at'. The parents considered whether a gastrostomy might be educationally and socially beneficial by allowing John to interact with his peers during school meals rather than concentrate on oral feeding. Here oral feeding was constructed as potentially exclusionary, preventing John from 'joining-in' the fun. His parents construct a choice between maintaining oral feeding, but at the risk of denying John his 'own space':

I just think though it's John not getting John's own space, which is, there's lots going on around him, there's other kids eating and drinking, and that's a far more interesting than eating your own food. And it's the difference between here normal feeding in the kitchen in his woosh [name of special seating] perhaps looking out of the window, doing whatever, or perhaps we'll eat together round the table, and that's the most active it gets. But at school I should think there's lots going on and to look at, um instead of eating properly, you know. [John's father, 1/1, pre surgery]

The idea of placing restrictions on children's learning originates in a child-centred pedagogy where force, coercion or restraint are seen to interfere with the child's natural capacity to learn and is discussed in more detail in the next chapter. Although John's parents do not mention the idea of force in relation to oral feeding there is an element of 'forced concentration' needed to get John to eat 'properly' (i.e. without choking). Oral feeding is constructed as restraining as it denies John the opportunity for social interaction with his peers. Piaget advocated spontaneity in relation to learning through discovery. Providing children with the conditions for spontaneous activity and allowing them to explore freely without intervention from adults is part of the pedagogy (Walkerdine, 1984). Concentrating on oral feeding then is akin to a form of rote learning (oral feeding doesn't come naturally it has to be rehearsed and learned), which runs counter to the naturalisation of feeding and the child-centred pedagogy for it is seen to coerce the child and stifle her natural expression.

In conversations with parents and carers, it was apparent that schools had different rules about tube and oral feeding. There were examples where tube fed children were separated from their classmates and taken to the sick bay for feeding. Here, gastrostomy feeding is constructed as a 'medical' task to be overseen by the 'medically' qualified. Similarly, there were examples where schools segregated tube fed children during mealtimes; children were fed as a group while listening to music or experiencing foot massage suggesting attempts at providing a compensatory, 'pleasurable' environment. Dayle and McIntyre (2003:316) in their work on child poverty and feeding programmes in Canada observed how 'strategies of power were embedded in the pleasurable environments of feeding programmes'. They argue that the segregated use of space allowed children to be observed and monitored and served a regulatory function through the differentiation of children who attended programmes from other school children.

Parents also mentioned that some schools operated policies placing time restrictions on mealtimes, after which children were required to sit in the playground. Most likely, the time limits imposed would be insufficient for a child with feeding difficulties to accomplish an adequate nutritional intake. Drawing on Foucault (1975), Dayle and McIntyre (2003:318) suggest that individuals are regulated through time management

which allows for the control of activities in the daily practices of techniques of power. Techniques of power serve to regulate and undermine parental desires for their children to be fed orally as both the rights of children and their parents become subordinated to institutionalised practices and routines.

The question of who is allowed to tube feed children in institutions is a complex issue relating to concerns about legal indemnity and resources for training carers (Townsend and Robinson, 1999:219). Townsend and Robinson note that Health Care Trusts regard aspects of feeding as social care tasks and expect to be reimbursed by Social Services for training staff. Conversely, Social Services see staff who tube feed as carrying out nursing tasks and as such expect free training and support. Further, whether tube feeding is defined as a nursing or social care task can affect the services families receive, which may vary depending on the policies of the health and local authorities where they live. Some families in the interview study experienced a loss of respite care following the insertion of their child's gastrostomy as a result of this bureaucratic wrangle. Unfortunately, families were rarely advised about these potential problems before surgery.

Conclusion

In this chapter I have discussed a number of reasons parents gave to justify their feeding practices. Their accounts drew on developmental discourses that constructed the ideal child as autonomous, independent and maturing towards adulthood. Concerns about children's exclusion from social and family arenas constructed gastrostomy feeding as a potentially exclusionary practice infringing the rights of the child. I have argued that involvement and participation (associated with feeding and mealtimes) are part of the process of preparing children for citizenship. This was particularly apparent in relation to language skills and children's rights to speak and participate, forging a link between women's parenting and the community.

Parenting practices therefore work toward the goal of cultivating independence in children achieved, in part, through feeding. Oral feeding is constructed as a learning

environment through which children can explore and have an effect on their world, either through play, the experience of food in the mouth, or the expression of a choice about when and what to eat. Development is associated with oral feeding which provides parents with feedback of their child's continuing progress. The 'mastery' of feeding skills, for example, signals an incremental progression - from fingers, to spoon to fork. This is exemplified by the incorporation of feeding behaviour in developmental scales used to measure the attainment of skills in relation to a series of milestones standardised on normal populations.

Mothers may continue with oral feeding following the insertion of a gastrostomy in their child because of the perceived developmental benefits and the project of cultivating independence. This is particularly pertinent in the face of the rhetoric of neo-liberal governments about the undesirability of a dependency culture. Hence the domestic economy becomes a site of regulation of mothers, with its focus on child-centred parenting, by blurring the distinction between women's domestic labour and opportunities for educational development (Walkerdine and Lucey, 1989).

Play experiences are also invested with ideas about the roles children are expected to perform in the future (I revisit the idea of informed consumer and active citizen in the final chapter):

Good play experience also supports the development of autonomous adults with a strong sense of personal identity, who are effective in society as parents, workers, informed consumers, active citizens, and a range of other roles. (National Playing Fields Association, 2000:14).

Moreover, play experiences are informed by the construction of the rational autonomous individual and reflect the core cultural values of liberal democracies – freedom and choice. Play: 'provides children with opportunities to enjoy freedom, and exercise choice and control over their actions' (National Playing Fields Association, 2000:11).

Ironically, institutional practices which serve to exclude children from classroom meals with their peers, or from specialist short-term care following gastrostomy insertion,

serve to undermine the discourse of rights, choice and freedom. Townsley and Robinson (1999:223) note that tube feeding is often used as a reason to exclude children from both mainstream and special schools on medical grounds. Although there is legislation designed to protect children's rights to an education and support, children are very often denied these rights.

In the next chapter I look at the extent to which expert advice, research and women's accounts of feeding reproduce the discourse of the sensitive mother. I discuss examples of force and coercion as contradictory aspects of feeding and caring which threaten the rights and autonomy of the child.

8. War in the kitchen

'Don't ask, bribe or force a child to eat' [Dr Spock, 1992:371]

Introduction

My title 'war in the kitchen' is a pun on Denise Riley's work, *War in the Nursery* discussed in chapter 6. Dr Spock's advice not to bribe, force or even ask a child to eat is illuminating for it begs the question of how a mother is to deal with a child that refuses to eat. Underpinning the advice is the concept of a child's 'natural appetite' (which equally applies to learning as well as feeding). The child-centred discourse constructs force as harmful to the natural unfolding of a child's curiosity, imagination, capacity for learning and desire to eat. This constructs the child as autonomous and agentic, acting on 'his' own terms without being pushed, forced or coerced, processes which are seen to interfere with the child's natural development. All that is required is the right learning environment which as I have argued is the responsibility of the mother to provide, particularly in pre-school children.

In the previous chapter I discussed how women's domestic work has become transformed into a pedagogy designed to aid the intellectual development of children. Walkerdine and Lucey (1989) suggest the discourse of the sensitive mother serves to regulate women who in turn regulate their children to produce the kind of subjects necessary to participate in a liberal democracy. The rise of totalitarianism was attributed to the failure of educational and child rearing practices, which de-politicised the social and economic conditions responsible for breeding facism. Pedagogy was therefore reformulated to produce individuals who were 'controlled but not regimented' (Walkerdine, 1990:7). The mother was seen to play an instrumental link between the child and the community by producing 'reasonable citizens'. Democracy was guaranteed by the removal of 'oppression, powerlessness, division or exploitation' from the domestic economy (Walkerdine and Lucey, 1989:101).

Scientific pedagogy, then, was about control through self regulation. Central to the pedagogy was the naturalised unfolding of the child's development. Pedagogy in terms of overt authority began to be challenged and educationalists advocated an education 'according to nature' which would ensure 'a natural path of development'. Further, children who were not overtly coerced would have no need to rebel: 'docile bodies would become a self-disciplined workforce' (Walkerdine, 1990:21). As Newson and Newson (1970:427) state:

Strict training in unquestioning obedience to an autocratic mother and father is no longer a normal or acceptable way of bringing up children in the climate of opinion which prevails in the English speaking world today.

Here the authors reinforce the notion of sensitive parenting, the standard against which all mothers are judged; authoritarian parenting is not only inadmissible, it is abnormal. Parenting practices involving coercion are therefore pathologised, but as stated in previous chapters the practices of working class and black families are more likely to be problematised for failing to meet the standards of sensitive parenting. Science has played an instrumental role in producing accounts of mothering and of mother love as natural, and therefore asserts a truth claim. However, science is not merely describing, but is producing and regulating mothering and this regulation serves the purpose of producing responsible citizens (Walkerdine and Lucey, 1989).

Threats to democracy are more obviously articulated in contemporary Britain in the designation of groups of people who do not participate in society as the 'underclass', the 'socially excluded', or the 'alienated youth', and is reflected in the low turn out during elections. The apparent lack of interest in the democratic process is laid at the individual. Measures to promote democracy are those which address social exclusion, either through punishing parents, encouraging or forcing parents to attend parenting classes, offering classes in citizenship and various types of community service.

In this chapter I look at the extent to which expert advice, research and women's accounts of feeding reproduce the discourse of the sensitive mother. I will discuss women's accounts in relation to coercive aspects of feeding which bring into stark relief the contradictions between discourses of the sensitive mother, normative

development, and the rights of the child. I argue that practices that are considered coercive, and therefore pathologised, are contradictory aspects of feeding and caring for children. I examine how contemporary constructions of the mother-child dyad fail to theorise the effects of parenting in the context of multiple siblings or children who receive care across multiple contexts. Further the liberal discourse of the rights of the individual fails to acknowledge that in meeting the needs of one person this may be at the expense of another.

‘Don’t make mealtimes a battle ground’: expert prescriptions

The comment ‘don’t make the table (i.e. mealtimes) a battle ground’ was made by a presenter on Breakfast TV participating in a discussion about children’s feeding and nutrition. I suggest that the pedagogy of liberation underpins this advice about feeding. By making mealtimes pleasurable, conflict can be avoided through play and fun. For example, Leach (1989:304) offers advice in her child care manual about mealtime behaviour, intended to address parental concerns about children who do not eat their food. A philosophy of child-centredness percolates the advice offered. The child, not the parent, should be the one who chooses what food to eat and decides when she has had enough:

When you say that he “ought” to eat everything on his plate, are you thinking of him having enough to eat or of “not wasting good food”? As we have seen, he is the one who knows whether he has had enough or not. As to wasting food, isn’t it just as much of a waste to force it down a reluctant child as to feed it to the cat?

The overall tone of the advice is that conflict and struggle should be avoided at all cost. The author cautions against choosing mealtimes as a forum for discipline – ‘you may pay a high price’ (Leach, 1988:304). She continues:

The more you try to impose rules and regulations on eating and table manners, the clearer it becomes to the toddler that the meal table is a marvellous place for a fight. Soon your child knows that it is a place where he can always get your attention and concern. That situation is irresistible to the child’s growing sense of his own power and independence. If you foresee the possibility of mealtimes becoming a battleground, you can stay one jump ahead by resolutely refusing to become involved (1988:305).

Again the invisible hand of power and covert regulation of children is favoured over overt discipline. The caption: 'let him enjoy eating in his own way. Green beans dipped in ice cream may be unconventional, but if that is what he likes...'; the sentence is deliberately left open and constructs the child as unique, free, in control, and the source of as - yet - unknown creativity and potential. Interference in the form of coercion is seen to disrupt the 'natural' process of development.

It is clear that trends in parenting practices are informed by class but vary over time. Newson and Newson (1970), in their study of four year olds in the sixties, found that the order in which food was presented was considered important by families in higher social classes, reflecting a greater emphasis on table manners. The authors concluded that middle class families positively valued the formal aspects of mealtimes. Given mothers were expected to entertain frequently, they were conscious of the need to socialise children in terms of appropriate mealtime behaviour: 'the formal social occasion calls for a greater ability for self-control'. Middle class families were therefore more likely to enforce rules about mealtime behaviour (Newson and Newson, 1970:254).

That working class families' practices are pathologised is evident in a more recent study looking at the role of psychosocial factors in contributing to growth retardation in children of manual workers (Heptinstall et al., 1987). The authors concluded that lack of parental care and family dysfunction, defined in terms of disorganised mealtimes and negative attitudes, were the most important discriminating factors in accounting for poor growth compared with a control group with a similar socio-economic status. Several observations were noted by researchers that are worthy of discussion as they resonate with, and therefore indicate the persistence of, deficit models of parenting typical of the 1960's.

The first concerns the observation that both case and control group showed 'little awareness of the principles of good nutrition' despite the fact that ideas about nutrition are highly variable and culturally specific. Nutrition is a site of government regulation and investment by big business. As such there is no objective yardstick by which to measure nutrition that is independent of vested interests. Food products considered

nutritious twenty or thirty years ago may not be considered so today²³ and the role of advertising in influencing food preference need to be considered (Meikle, 2002). Children's breakfast cereals, often advertised as healthy, have recently come under scrutiny for their high fat and sugar content. However, it would be difficult to counter the effects of advertising, marketed specifically at children with the offer of free gifts and action packed excitement invested in the consumption of the cereal, the packaging (often with cartoons and games) and the 'freebies', with a piece of healthy fruit (Tapper et al., 2003). The rights of the child to consume are clearly at odds with the mother's responsibility of ensuring a healthy diet.

Many families may not have a lot of choice about what is on offer, how it is offered and in what order. Families living in bed and breakfast accommodation, or poor housing generally, may not have access to cooking or dining facilities, or the kind of resources that might allow women to exercise the advice offered by the experts about appropriate nutrition and mealtime behaviour. Messy eating may not be tolerated where there is a lack of washing facilities. Real disposable income, access to affordable credit, transport (making it easier to access supermarkets where food is cheaper compared with local shops) and issues of personal safety (discussed in the introduction) may all affect the principles of nutrition.

Similarly, in the gastrostomy interview study although women were aware of the principles of nutrition, when faced with a child that refuses to eat these were abandoned in favour of more practical concerns of getting a child to eat anything at all. One mother spoke of feeding her child nothing but chocolate and halva and felt guilty about the affect on the child's teeth. Food of a high calorific density might not be nutritious but it 'kills' hunger and helps children gain weight.

A focus on the deficit skills of parental knowledge fails to appreciate the socio-economic and political context of food, feeding and nutrition. The Child Poverty Action Group estimated that one in three children (4.3 million) were living in poverty in

²³ I am reminded of my domestic science teacher at school telling us that fish, chips, and peas contained all the right nutrients for a well balanced diet only to be told by a Conservative Politician some years later that Northerners should stop eating this kind of 'unhealthy' food.

1999/2000 (Howard et al., 2001) and approximately 50,000 children in Britain between the ages of eight and ten have nothing to eat or drink before going to school (Piachaud, 2000). Moreover, one study reported that parents of disabled children spend twice as much on comparable items (accounting for a fifth of total family income) as parents of non-disabled children (Dobson et al., 2001). These factors suggest that nutrition is more than a matter of parental education and policies aimed at women to improve family nutrition will fail in the absence of commitments to tackling poverty. The Heptinstall study, however, did note that children's poor oro-motor skills were probably due to a lack of experience with food of different textures which was attributed to budgetary restrictions, acknowledging that material conditions do play a role.

The second point resulting from the Heptinstall study concerns the observation that mealtimes were characterised by 'disorganisation' and 'negative attitudes'. Case group families were not seen as treating mealtimes as an opportunity to communicate. In fact there was communication, but of the wrong sort –anger, tension, chaos, and force-feeding. If parents were not present at the table, rather than viewed as an example of permissive parenting and child autonomy, unsupervised feeding was seen as indifference on the part of the parents. Chaos was defined in terms of children wandering around while eating (compare this with the permissive advice of Penelope Leach not to force children to sit at the table). Again it is worth comparing these observations with those made by Newson and Newson (1970); working class families were more likely to have rules prohibiting verbal exchanges given the main purpose of mealtimes was eating. Talking was encouraged after the meal rather than during. Conversely middle class families were more likely to view mealtimes as a social occasion and a time for family conversation. However, middle class families were more likely to enforce rules governing mealtime behaviour.

When working class families enforce rules, their parenting practices are condemned as coercive and negative. The effects of economic factors in contributing to tension and anger are rarely explored however, nor is the possibility that poverty causes families to be dysfunctional. Rather poverty and tension are sanitised and re-defined in terms of deviance. As Urwin (1986:275) notes, developmental psychology is dominated by:

‘the disappearance of aggression from the harmonious, tension free account of the normal mother-child relationship’. When aggression and tension are evident, the family is pathologised.

Force-feeding: Whose rights?

Although families spoke about the importance of including children in the family meal, Patrick was able to indicate his preference not to participate because of his aversion to food and oral feeding. Following the insertion of the gastrostomy, Patrick refused to eat by mouth. The significance of oral feeding was apparent in the way the mother related a conversation she had had with a dietician who had asked her to consider whether it was fair to keep pushing Patrick to eat when it made him so ill. Although both parents found the prospect of Patrick not eating difficult, the mother (her partner suggested) found it harder. She attributed this difference to the importance of meals as a ‘social’ occasion. However it was apparent that Patrick did not enjoy being around food. For Patrick there was no social side to feeding:

- M: And then the dietician that we had locally, she's really good and we've known her for a long time now and um, she put it on, Patrick's perspective to me, you know. Why do you think he's eating? Is he eating for himself or is he eating because you want him to eat? Um and if he really doesn't want to eat is this fair to keep pushing it and pushing it and making him feel so ill? And I think that's what...
- F: We found that harder, you found it harder for him to not be eating than I did, I don't know why I mean
- M: I think part of it was the whole social thing, because now if he's sitting with people (...)
- F: He doesn't want to be around people that are eating
- M: I don't know if it's the smell or whatever but it makes him feel ill, so, umm, even at school now they've finally realised that it makes him feel sick.
[Patrick's parents, 1/1, post surgery]

Although Patrick had ‘lost’ the social function of mealtimes, his mother accepted that this was his choice (‘I think he's quite relieved that I'm not making him do it any more’, ‘I think it's me that finds it more difficult than him, on that side’). The example is illuminating as it illustrates the conflicts inherent in the liberal discourse of rights and responsibilities; the child's right not to eat, not to be around food, and the mother's

duty to ensure the child is included in family life. Again inclusion is constructed around family mealtimes:

- M: it's accepting they're not going to eat, that's hard. That's very hard. I mean with Patrick, you know, as I said it's more of a social thing than anything else and then I feel he's lost that, although I don't think Patrick feels like that now. I think he's quite relieved that I'm not making him do it any more. And then at Christmas I bought, cos he used to love Marks and Spencers lasagne. For him that was the best thing you could ever buy him, that and a chocolate pudding for afters, so I bought him for Christmas, thinking, you know, Christmas dinner and I'll give him something that I know he likes. But he didn't want it.
- G: He doesn't eat anything now then?
- M: No, no. I mean he had two or three mouthfuls, you know, but you could see, his whole face, he really didn't want it. So.
- G: When you have meals, how do you arrange it all then? You feed Patrick first?
- M: Well no, cos now he's on the pump all the time now, so um, when we eat now, he prefers to, he likes to come out of his wheelchair for a stretch, so now he goes into his bedroom. That's what he wants to do, he just lays on his bed and watches television. He can turn his television over with his remote control, or watches a video or chooses music, or, you know. He does what he wants to do, so um, he's quite happy. I think it's me that finds it more difficult than him, on that side. [Patrick's parents, 1/1, post surgery]

Although Patrick was doing what he wanted by sitting in his room and watching TV, his mother found this difficult. When I questioned her about the reason for her difficulty in accepting Patrick's decision not to take part in the family meal, she spoke about family meals as something habitual from her own childhood. She therefore designates the family meal as the place for social interaction. As Probyn (2000:37) states, 'nostalgia: for eating and togetherness' is epitomised by the family. However, 'familial eating and the ideology of the family-that-eats-together have been largely under-theorised' (2000:38):

Because mealtimes are important, you know, we all sit at the table and the other three children, you know, we all have the mealtimes together and we sit at the table um, and they're not allowed to have the television on and things like that, you know. And we talk about what's happened at school and you know, and it's always been an important part of the day. And I suppose Patrick's lost that as you know, part of the family. I mean, we still do loads of things with Patrick as part of the family but that's one thing that you know, I've always made sure that you know especially the evening meal is all together, and he's not. I think that's just something from my childhood, you know, you sit at the table and you eat. He doesn't like coming into the kitchen when we're eating, and he doesn't

particularly like coming in when we're cooking. [Patrick's mother, 1/1 post surgery]

Patrick's parents reported that the gastrostomy had improved Patrick's quality of life because feeding was no longer a 'battle'. Again feeding experiences were described in duplicitous terms, as both special and war-like:

F: Well he hasn't got, food isn't an issue now is it

M: No

F: I mean, we're not making him, we're not doing something that he doesn't want

M: Between me and him, feeding became a real battle, because I was 'you are going to eat' and he was 'I don't want it', and I'd end up storming out of the kitchen, you know 'I've had enough, I can't cope with this any more' and he'd be in tears. Oh, it was awful, it was horrible, not just for me and Patrick but for the other kids, I mean, [name of sibling] was saying 'but if he doesn't want to eat, Mummy' and I said 'well he's got to eat, if he doesn't eat, you don't live if you don't eat, you know!' It was horrible. [Patrick's parents, 1/1, post-surgery]

Patrick's mother constructed her battles with feeding as having detrimental effects on the other children. Similarly Judy's mother reported that her son had begun to mimic Judy's refusal of certain foods. As Probyn (2000:38) notes, the 'power-plays that structure familial eating' contrast with the idea of comfort eating and the idea of mealtimes as pleasurable. I discuss the impact of feeding on other siblings in order to extend ideas about feeding beyond the mother-child dyad later in the chapter.

Accepting that, given a choice, a child preferred to be fed by tube was often hard for mothers as it raised the issue of whether the child had ever enjoyed oral feeding prior to surgery. One mother told me that she always gave her child the choice between the tube and oral feeding. However her disappointment was very apparent when the child indicated a preference for the tube.

Patrick's mother's account of the battles over feeding would not accord with the idealised image of the family meal she seeks to re-enact. Nor would it comply with the expert advice not to make mealtimes a battleground. Dr Spock (1999:367) cautions: 'The balky child who is challenged to a feeding battle can always outlast a parent. You don't want your child to eat because she has been beaten in a fight, whether you have been forcing her or taking her food away'.

As discussed in previous chapters, women's rationales for oral feeding were informed by wider discourses of the family, child development, disability and mothering. The coercive aspects of feeding children (both orally, and using a nasogastric tube for example) bring into stark relief the contradictions between discourses of the sensitive mother, normative child development and the rights of the child.

Garry's mother constructed oral feeding as force-feeding because of the humiliation involved - in terms of a child 'coughing' and 'splurting'. She justified the use of force as a means of ensuring Garry obtained 'the right amount' (of food). Although oral feeding was important to her, she accepted that the gastrostomy was a way of helping Garry. It also took the pressure off oral feeding by offering Garry 'tasters' and 'favourite snacks' without resorting to force. Force is associated with the quantity of food needed to sustain Garry, which nicely illustrates the confounding of care and control.

Garry's mother constructed the scenario of disabled children eating in public arenas as 'more humiliating' than a child fed by a nasogastric tube. But why should this be the case?:

And when he got to three and he wouldn't take his feeds orally that really upset me. Um, for the future, I'm, I think that it would still, I would be, I am sort of upset about it but not too upset because I've found a, a sort of a solution to help maintain, as long as he's getting food, that's my main priority. Not so much the fact that he's not taking something orally. I mean, they've found a way to help him, um, I don't feel, I feel that when I'm giving him his feeds orally, tasters, or if he's having his favourite snack, I'm not having to force it down him, and that's the difference because when I used to feed him orally, there were times I had to force-feed him, just to see, to make sure he gets the right amount of food. That was one, and two, if I had to go out I didn't want to be going out and doing this. Because I had spoken to other mothers but they said they feed their child orally in public and the child is coughing and splurting and it's, and I feel, I feel that's more humiliating than um, if I'm feeding him through a nasogastric tube with a bolus feed, I just feel, I don't see why Garry has to go through that. And he hated it when I had to force-feed him. He didn't, he was not happy. [Garry's mother, 2/2]

Humiliation is a discursive practice (Law, 1999). In this example, it works to reinforce the discourse of sensitive mothering by regulating women's mothering. Humiliation not

only regulates mothering but is used by women to regulate other women. Law refers to this as a 'twin discursive practice' (Law 1999:120), whereby a woman can feel 'humiliated' by a child's abnormal feeding (the mother is the object of the discourse), and women can humiliate other women on account of their children's abnormal feeding (women are the subject of the discourse). The discursive practice does therefore constitute a form of censorship; it was discussed in chapter 6 in relation to the ease and convenience associated with gastrostomy feeding. A mother who orally feeds a child 'using force' is stigmatised by a regulatory discourse of mothering that proscribes conflict and coercion within the mother-child relationship. A woman who coerces her child is condemned for her lack of sensitivity and for compromising her child's autonomy. Conversely, the sensitive mother avoids conflict which masks her power.

Humiliation vis-à-vis force threatens a child's sense of autonomy by rendering her powerless (Walkerdine and Lucey, 1989:27). However, as already discussed, a disempowered child is seen as a threat to democracy by creating the conditions for rebellious or delinquent behaviour. Parenting therefore must be free from overt control. The child's sense of agency must be preserved at all costs. Battles over feeding fail to accord with the regulatory discourses of sensitive parenting and child-centredness.

Alternatively, Paul's mother constructed gastrostomy feeding as a form of force-feeding because it supplants a child's natural appetite with a mechanistic form of feeding. In short, she constructed the gastrostomy as depriving Paul of his right to choose whether he wanted to eat based on his own bodily sensation of hunger, especially if ill:

I think Paul knows what's good and what isn't with him. Because actually when he's not feeling very well he will turn round and say he doesn't want to eat, he doesn't eat all the time. You know if he's slightly under the weather he'll turn round and you know I'm not having it, and I let him decide how much food he wants. He knows his own appetite, he'll know if he's very hungry and wants to eat a lot, or if he's not feeling so hungry and doesn't want to eat a lot. And that's the other problem I have with the tube, that most feeds are like that, and actually if you've got a child that's ill to force feed stuff down a tube, and you don't know whether it's body really needs or not, because it can't indicate to you, you could end up causing more problems they just end up puking the whole time, and that in itself would cause problems with the stomach lining to keep on retching. It doesn't do any good. So I suppose another reason why I'm

quite keen to continue the oral feeding because I think it's Paul's way of telling me what he needs, because I think he does know his own body, he knows, you know like all of us you know what's good for you when you want to eat and when you don't want to eat, and if he doesn't want to eat I don't force it on him.
[Paul's mother, 2/2]

The first sign of child illness is often poor appetite. Parents usually modify the child's diet and relax the usual routines around feeding. For Paul's mother the idea of feeding a sick child by tube, in the absence of any indication of whether or not he wants or needs food, threatens his sense of autonomy. The ability of a child to express a choice about feeding is taken as evidence of growing maturity. Feeding in response to a child's needs ('he knows his own appetite', 'it's Paul's way of telling me what he needs', 'he does know his own body', 'I let him decide') constructs Paul as autonomous, agentic and in control of his feeding. As Walkerdine (1990:9) states, 'the pedagogy of choice is a tool in the production of the rational ideal'.

Paul's mother drew on a body machine metaphor to describe the perceived damage of force-feeding a child – it could cause problems with the stomach lining through over feeding which might result in retching and vomiting. In short, overfilling the body will result in the system overheating. The child is able to ensure the system doesn't malfunction by exercising choice and free will in relation to whether he feeds or not. Self-regulation in relation to behaviour in general, and food in particular, is an important characteristic of the autonomous child. In contrast to Patrick's mother, if Paul doesn't want to eat, his mother doesn't force him.

Paul's mother also constructed the gastrostomy as something that would help Paul become more self-reliant by breaking the dependency on his mother for feeding, particularly, when taking liquids:

So my husband will be delighted because we can be more independent and at the moment there's only one carer I can leave Paul with when it's time to have a drink, and if she's not around then I can't leave Paul. So he has an incredible dependence on me, which we need to wean off as well. I mean I know, kids that I know who are, but I want Paul to be independent and the gastrostomy's a way of him getting more independent because then most people can feed him because he's actually not too difficult to feed. He can feed in his chair, and if he

doesn't have to be on someone's lap to give him a drink then he can spend more times off our lap, more time on the equipment. [Paul's mother, 1/2]

The project of making Paul independent and autonomous can be achieved therefore through both oral and tube feeding. Oral feeding allows him to exercise choice and free will. Tube feeding allows him to be less dependent on his mother for liquids. His mother also spoke of the difficulty of accepting medical advice not to feed orally because: 'Paul doesn't recognise anything coming by the tube is filling him up'. Again she appeals to the idea of the child's natural ability to experience hunger and satiation, which is experienced through the mouth and not through the tube. The difficulty of denying Paul 'normal' food, for example 'toast' when he asks for it, and enforcing tube feeding when he refuses to be fed by tube, overrides his right to choose what and how he eats -the 'child first and always'.

But no, on the whole it's been a great benefit, but as I said the wind is still bad, and also you have a big debate we have as how much to give him normal food and how much to give him by the tube. Because of course the medics all want us to give him by the tube, because of fear of aspiration, but Paul doesn't recognise anything coming by the tube is filling him up. I mean I was giving him a full strength feed this morning and he was just shouting at me while I was giving it to him, he didn't want it, he wanted toast. He doesn't get any satisfaction from his stomach, he hasn't recognised that that gives him satisfaction to have that tube. He knows it's fine with drink and he'll tolerate it, but he won't say oh whoopee I'm going to get a feed, it's like you give me stuff through the mouth as normal please. But yeah, so you know it gives him more independence, gives us more independence, gives him better nutrition, I think his immune system's working better for it and I think it's overall been of great benefit. [Paul's mother, 2/2]

Conversely, the idea of using force in order to instigate oral feeding when Paul was a baby was justified on the grounds that Paul 'did start to learn how to swallow'. Coercion is justified, in other words, when the express aim is to cultivate skills that 'normalise' development, that is, engender autonomy and independence:

[we were] trying to get him to drink out of the bottle and after that, his fifth or sixth day at home he ripped out the tube [NG] himself and I thought oh God, you know faced with putting this wretched thing back in and that evening he'd had a full bottle of milk by the bottle. So I'm afraid [we] were perhaps a bit cruel to be kind and just turned round and said that's it, no more tube, right mate another bottle and we forced him to do it and I used to have the same hat as I

have now, I mean that's probably why he is so anti feeding because we forced him with that, but actually I think it was probably the right thing to do. It might have been in fact a bit premature but I think it was the right thing to do because he did start to learn how to swallow, he had to, and of course everyone was panicking about aspirating, but actually he wasn't getting infections, he was managing it, because he has actually got quite a good cough reflex and then while he was on the bottle I don't think he did aspirate. [Paul's, mother 1/2]

The idea that it might be necessary to be cruel (the denial of food through the NG tube) in order to achieve a greater benefit in the longer term (learning to swallow and become self-reliant), contrasts with the notion of the child's right to choose how he feeds. Presumably a baby is not capable of making that choice and the parents made a judgement that oral feeding was in his best interests. Paul's 'natural' (in)ability to feed was discounted (that is, the parents did not accept that Paul couldn't feed and that this might be a natural state for him) in favour of a feeding regime (oral feeding) imposed by his parents. This contrasts with his mother's reluctance to impose a regime of gastrostomy feeding. The comment – 'that's why he's so anti-feeding' - contrasts with the assertion that Paul enjoys feeding, and if he were deprived of the opportunity to eat orally he would almost give up on life (see chapter 7). The contradictory effects of parenting and child-centred discourses are very apparent in these examples.

There were other examples where parents tried to promote their children's 'natural appetite' or feeding skills through a 'cruel to be kind' philosophy; the removal of NG tubes and 'starving' children until they were sufficiently hungry to want to eat, for example.

Patrick's mother however, did not construct the gastrostomy in terms of force-feeding, rather she represented it as an alternative way of feeding:

Now, you've got the chance where they can be fed in an alternative way, and we've had people saying oh, it's force-feeding. It's not though, it's an alternative way of eating, it's not force-feeding. [Patrick's mother 1/1, post surgery]

In the follow up interview with Zarra's mother, she recounted the pressures of feeding Zarra, often imposed against her will ('without [her] feeling it or without wanting it'). Although the mother continued to struggle with oral feeding during the day, she

reported that there was less pressure as they had the option of feeding by tube overnight. As such, the tube allowed Zarra to be treated like a 'normal' child. Normal is defined in terms of child-centredness - 'she eats whenever she wants' as opposed to her mother 'pushing her to eat' ('I just leave it to her to ask for it'). However when I asked the mother the reason why she persisted with oral feeding, she explained that there was no reason why Zarra shouldn't eat orally-'she's got no obvious problem'. She again constructed the gastrostomy as something not normal. The gastrostomy then allows Zarra to be treated as a 'normal child', while at the same time constructs her as not 'normal'²⁴. The contradictions are explained in terms of the way discourses of child development construct the child as normative and regulate women's parenting practices

- M: Now at least I can, I can wait until she asks. I mean she doesn't ask very often but it doesn't mean that whenever she's asking for it she'll have it. But at least it's not like me pushing her, I mean without feeling it or without wanting it, because I was too worried she doesn't have enough er, what, enough food to keep her going. So now it's like taking it easy, I mean, I'm treating her like a normal child, she eats whenever she wants. I mean, that's what was happening anyway before, it's just there was pushing, I was, I don't know, making more fuss maybe about it. Now it's started easing off and maybe she likes it more because she doesn't feel like everybody's telling her what to eat, when to eat and stuff. She, I just leave it to her to ask for it.
- G: Okay. And you said before you're not going to feed her completely by gastrostomy, you want to maintain oral feeding
- M: Yeah, yeah
- G: Why, why is that, what are the reasons because sometimes some doctors say, 'well put all the food in the gastrostomy' and, some, you know, parents say no, I don't want to do that. What, what does it sort of?
- M: Well because I mean, I would like her to be as normal as possible, I mean relying totally on the gastrostomy I don't think it's an option for us anyway, and er now, I wouldn't think about it. [Zarra's mother, 2/2]

However, the difficulty of maintaining a philosophy of child-centredness in relation to feeding is apparent in the way Zarra constructs feeding as a game. The 'playful' side of feeding is not experienced as a special time by Zarra's mother who constructs Zarra's attempts at play through feeding as a form of manipulation. Whereas before surgery

²⁴ That a tube constructs the child as both normal and not normal is important when considering more conventional approaches towards the measurement of attitudes where respondents are forced to make a choice by endorsing a statement with one response. The attitude literature presupposes that attitudes are unitary, fixed and invariant. However, this example challenges the idea that attitudes are unitary, suggesting attitudes are an artefact of the way they are measured (Stainton-Rogers et al., 1996).

Zarra's mother always responded to her child's demands, following the insertion of the gastrostomy, she felt more in control as she tried to 'normalise' feeding by imposing limits on Zarra's eating behaviour in terms of what, and when, she ate. She therefore resists the regulatory aspects of the child-centred discourse.

For Zarra's mother, the ability to control Zarra's feeding and resist her constant demands for food positions her as a 'normal mum' with a 'normal' baby. This contrasts with the previous extract where 'normal' was defined in terms of child-centredness ('she eats whenever she wants'). The difference is that prior to the gastrostomy the mother could not resist Zarra's requests for food in the absence of an alternative method of feeding, whereas following surgery she had the option to resist those demands – thus feeding at 'her own convenience' rather than her child's.

Zarra's feeding before the gastrostomy resonates with breastfeeding on demand. Balaskas and Gordan (1992:198), in their 'baby book' suggest: 'the easiest approach to breastfeeding is to be prepared to feed your baby whenever he wants'. Zarra's mother reported 'feeding on demand' far from easy but felt she had little alternative. Placing limits on a child's behaviour might not meet with philosophies of child-centredness and sensitive mothering, but there may be times when mothers cannot fulfill children's needs in the ways prescribed by the experts without great costs to themselves:

And er, er I'm like, I mean before, even if she plays with food I wouldn't take it away from her or like she keeps telling me, I mean, I was very aware of it, I mean, she would ask me for one thing, it takes time of course to prepare it and give it to her, then as soon as I put it there in front of her she would say no, she wanted another thing. I couldn't afford to say no, no way, I mean whatever time she asked for food, whatever she asks for, I would just go straight to the kitchen, prepare it and put it in front of her and hope that she would eat it. And I mean, 90% it was, I knew that she wouldn't eat it, that she's just playing and she knew how to, she learned how to manipulate me, I mean she just wants attention she will ask for food, not that she's hungry or that she's really interested but she knows that I wouldn't say no. Even if I'm in bed she will just ask for food and she knows that I just get up and give it to her. Now um, I feel I'm more in control. I mean, if I feel she's not interested or if the food is there and she's playing, I can take it off her, and tell her that if she's not interested she can't carry on playing with it. Or if she asks straightaway for another thing and I know she's not interested I can say no, you can't have it now. Or if she asks for chocolate just before going to bed I can say no, you can't have it now. I mean not like before, I would give her anything whenever, whatever really. But now

I feel um, well, more like normal mums with normal babies. [Zarra's mother, 2/2]

The gastrostomy therefore allows Zarra's mother to be in control. She has more control over the type of food she gives Zarra, including the withholding of food not considered nutritious. This control positions her as a 'normal' mum with a 'normal' baby. However, there is a cost to this normalisation, for as we have seen a feeding regime that does not place the child's needs at the centre invites accusations of selfishness.

I move on to discuss issues around feeding disabled children in the context of other siblings.

Challenging the mother-child dyad

I have suggested that one of the major criticisms of British Psychoanalysis is the way women have been positioned as objects of children's developmental needs without acknowledging the role of other family members, grand parents, friends and other contexts where care is provided. With changes in household composition (increases in lone parenting, divorce, and second families), children may receive care across different households (Office for National Statistics, 2001). Disabled children in particular may receive 'unorthodox' packages of care as a result of having personal carers, either at school or in the home, respite care and other forms of residential care. Further different carers may adopt different feeding practices often at odds with the parent's wishes, as discussed in chapter 4. The idea of the 'one to one' mother and child caring relationship needs to be taken in the context of who else can, or does, provide care.

The rights of siblings

Parental accounts of children's development were informed by the liberal discourse of rights: the right to a 'normal' childhood and 'normal' development, the right to eat or not to eat etc. However, disabled children may have other brothers and sisters who also

have rights. The question of whether meeting the needs of one child may be at the expense of another's and how the discourse of rights deals with this is unclear.

Research based on the mother-child dyad is not only an artefact of that relationship, but precludes a discussion of the cultural context of parenting and development and raises concerns about the applicability of developmental theory to other cultural contexts. For example, Piaget's theory is considered to be universal but there are debates about whether this model of development has relevance to other cultures (Dasen, 1998). Similarly, tests standardised on Western populations continue to be used across cultures, despite increasing concerns about their appropriateness (Pakendorf and Alant, 1997).

One example of the limited applicability of developmental theory to other cultural contexts is apparent in relation to social economic status (SES). Bradley and Corwyn's (2002) review of the relationship between SES and child development found that parenting practices were implicated in children's academic performance. The authors suggest that the relationship between language, cognition and the home environment, although complex, is influenced by factors such as overcrowding and the number of siblings, which can influence the quality of exchanges between parent and child, and ultimately academic performance. The authors argue that a greater number of siblings make more demands on parents who have to divide their attention amongst the different children. However, Holding et al., (1999), in a study of the effects of malaria on children's cognition in Kenya, found that the more siblings children have the better the cognitive performance. This is because there is an established pattern of caregiving from siblings in pre-school rural society, and it is not unusual for a sibling to assume the role of caregiver. Examples of cultural variation provide alternative models of parenting to the mother-child dyad. As Gittins (1985:68) suggests, to view the mother-child relationship as the universal nucleus of the family is to 'attribute to it a social and cultural significance that is lacking in some cases'. A focus on the mother child-dyad precludes a discussion of how women parent in the context of multiple siblings. I now discuss the impact of caring for a disabled child on their siblings.

Cohen (1999) suggests chronic illness in children places parents at risk of mental health and marital problems (although, as we have seen, material circumstances may play a significant role in negating these effects, and marital problems are not the preserve of couples with disabled children). The author also suggests that research practice continually reinforces the focus on maternal mental health because women tend to be the major participants in research studies.

Indeed this relationship was reproduced in the clinical evaluation where the major caregiver was required to complete the questionnaires. Of course as the major caregivers were women, the majority of questionnaires were completed by women (93.8%; 60/64). The effect of a disabled child on other family members therefore tends to be under researched. Lequerica (1992) questions whether the 'stress and loss' model of disability is appropriate to all cultures or classes, arguing that disability tends to be accepted, rather than challenged or feared in Latino families of lower SES, compared with mainstream Americans.

These different experiences were also reflected in parental accounts. For example, whereas one mother held a negative view of the impact of a child's disability on her sibling, – 'he knows her medication off by heart. Is that normal?' - others viewed exposure to illness, medicines and a medical environment as beneficial. If, as Walkerdine and Lucey (1989:66) suggest, women's domestic work is transformed into a pedagogy through play such that counting the cutlery while laying the table becomes a lesson in arithmetic, why doesn't this mother construct the child's ability to remember his sister's medication, including dosage, as a learning achievement? Is it because she lacks the creativity to turn her daughter's illness into a learning opportunity for her son, or is she reproducing the construction of the idealised child, pure, innocent and protected from illness and death? Fantasy role play, such as doctors and nurses, is usually accepted as part of children's play, but when children enact a caring role this is constructed as an infringement of their rights despite the fact that many children do care for other siblings, or parents and relatives in Britain (Centre For Child and Family Research, 2002), and in other countries. Children as carers subverts the adult-carer/child-cared for binary and challenges constructions of the idealised child.

That illness or disability can provide an opportunity for play and learning was evident from the way Patrick's siblings – Jack, Chris, and Beverly - incorporated their brother's disability into their play; Chris uses the tube as a washing line. Jack demonstrates his medical knowledge when playing doctors and nurses, 'he was a fantastic duty nurse'. Patrick's disability was not constructed as having a negative affect on his siblings:

When Jack was at nursery and they used to play doctors, they said they couldn't believe it because he'd say 'I'm going to take blood. Now if you sit very still it'll sting a little bit but it'll be over quickly' and they were saying, most children say 'this won't hurt' but he's heard it too many times! At three year's old Jack was a fantastic duty nurse. He used to open packets and drop it on the sterile table for me! Three years old! Unbelievable, isn't it eh? Beverley, my daughter's four, she wouldn't be able to do it, she'd have to 'touch' things! What children know, because it's what they're brought up with. I mean, Beverley knows not to pull the tube, Chris doesn't yet, but Chris is only 20 months, and I caught him the other day putting flannels across the tube because he thought it was the washing line, oh God almighty! But Beverley knows that you don't pull it and she also knows all the little alarms when you turn it off. But what she forgets to do is to actually come to tell Mummy that she's turned it off. [Patrick's mother, 2/2]

Conversely, Paul's mother constructed her son's disability as having a detrimental affect on his sister. Spending prolonged periods of time feeding Paul diverted time and attention away from Alice. The mother constructed the problem as one of how she divided her attention between the two children:

G: What about other members of the family then? What have they felt about the gastrostomy?

M: Well the other problem we've got with of course Paul's feeding and I ought to mention, is that basically he will only take a drink from me and his old school carer, who's since left, and now I've got one of those carers at home who's known him since eight months. She gives him a drink and he will take a drink from her. But he will not take a drink from anyone else, my husband he won't take it from, and Alice of course gets very jealous. I've got a younger daughter who's three now and she gets quite jealous about the amount of time it takes me to hold this one up and give him a drink, and also when she's, I can't do anything, and you know she can't play with her drum or whatever because the noise upsets him when he drinks. So you know she's actually had to be very tolerant because I must spend a good, well I should think it must take about two hours in a day giving Paul his drinks overall, and I need to get the right amount of fluid down him, and that's two hours in which she doesn't have access to me and she has to be quiet and all the rest of it and that's a bugbear for her as well because obviously kids want to have reactions like that (...) and obviously in holding the older child, and there's enough of that kind of jealousy issue

anyway, but it's made aggravated by the drinking problem I'm sure. [Paul's mother, 1/2]

Caring for Paul was constructed as having a detrimental affect on Alice in terms of her not having 'access' to her mother for 'two hours' a day, not playing with her drum because 'she has to be quiet' and 'tolerant' and hence modify her behaviour. Alice's right to attention from her mother, and her right to play is compromised by Paul's need to be fed. The constraints on Alice's behaviour are perhaps attributable to her gender (i.e. Alice has to be quiet and tolerant), rather than her brother's disability. What is unusual is that Paul's mother is able to calibrate Alice's 'deprivation' in terms of time (two hours) where she is denied access to her mother. Mothering is constructed as mutually exclusive: being available to one child precludes being with another, for the sensitive mother cannot be available to both children simultaneously in a dyadic relationship. The conflict the mother experiences is not so much the result of having a disabled child as a failure of the developmentalists to theorise mothering in the context of multiple children. If the presence of the mother alone is insufficient, and it is the quality of the interaction between mother and child that is important, the developmentalists need to theorise how one person can interact with a number of children of different ages with 'unique' needs without detriment to any one child, or the mother. The inability to theorise horizontal relationships between siblings serves to continually reinforce the importance of vertical relationships, usually between the mother and child.

The experience Paul's mother describes is perhaps not so dissimilar to that of other families with the arrival of a new baby, or multiple births. Alice's experience of jealousy is perhaps more attributable to her age than her brother's special needs and reflects the fact that young children are dependent on adults or other siblings for their care in general. Competing demands for attention are not unique to children with a disabled sibling. However, discourses of disability construct children with special needs as taking 'resources' away from other family members and fail to acknowledge the way family relationships are structured by class and material factors. I discuss this further in chapter 11.

Post-operatively, Paul's mother constructed the gastrostomy tube as advantageous because it not only allowed her to spend more time with Alice, given Paul could now be fed by other family members and carers, but the tube also enabled Paul to attend school on a full time basis. The mother's freed-up time is then diverted towards Alice.

Conclusion

Faced with a child that refuses to eat, a mother is faced with a stark choice. The child can starve, be coerced into eating or fed by tube, all options that are constructed as undermining the child's autonomy for different reasons. Whereas nasogastric tubes provided an alternative means of feeding, this did not always resolve the 'battles' associated with oral feeding. Moreover, parents often resorted to 'force' to insert the tube, or preventative methods, placing mittens on children's hands or sometimes tying the hands of the child down at night, where children pulled the tube out. Such practices can be construed as interfering with a child's natural sense of curiosity and play, which are considered to be important aspects of children's development. I discuss care and restraint in the next chapter.

Ironically then, coercion and force in relation to different feeding practices become contradictory aspects of feeding and caring for disabled children. 'Force-feeding', either orally, or with tubes, is seen as undermining a child's sense of autonomy- the very thing the developmentalists were keen to script out of the mother-child relationship. Conversely, denying a child the 'right' to eat food orally is also constructed as interfering with a child's developmental progress towards the goal of independence and self-reliance. Under these circumstances, mothers may find themselves in a catch 22 situation, trying to meet the conflicting needs of their children. Mothers are presented with an emotional quandary: 'harming' a child through 'force-feeding' goes against the discourses of the sensitive mother and the rights of the child, but failing to feed a child orally goes against the discourse of the sensitive mother and the rights of the child. Professional discourse offering expert prescriptions about feeding often add to these conflicts with advice not to feed orally, or to feed more.

In the next chapter I examine the way women's constructions of feeding technologies are seen to transform children rendering them Other.

9. Transforming the body: changing identities

Introduction:

When I was a child I used to watch a television series called the 'Six Million Dollar Man'. The series was about a man who, following an accident, lost the use of his legs and one of his eyes. However, all was not lost as a group of fictional scientists confidently asserted: 'We can rebuild him. We have the technology'. They reconfigured him with super-human powers. His bionic powers gave him capabilities that exceeded those of any of his contemporaries. He could see objects at extraordinarily long distances, far beyond the reach of the human eye. The Bionic man represented advances in modern Western technology. Advances in science lead us to believe that a cure for any illness or disability is not only desirable but will be found at some point in the future, given time, and that a person can be rebuilt and made to function as good as, if not better than, before.

The example of the Bionic man resonates to some extent with contemporary debates about bodily technologies, including gastrostomy-feeding tubes. Bodily technologies 'are regarded as the solution to the problem of the deviant body' (Valentine, 2001:45). Children with neuro-developmental disabilities are unable to achieve an adequate nutritional intake by oral means. Advances in medical science offer to reconfigure a child with an alternative way of feeding. However, unlike the Bionic man, the decision to 'rebuild' the child, both literally (through weight-gain) and metaphorically, raises ambivalence in parents about the potential for change. Yet to some extent children are already technologised with the insertion of grommets, shunts, and cochlear implants. The idea that the Bionic man would refuse the technology offered to him was inconceivable. Similarly, for many health professionals the idea that parents might resist the recommendation of a gastrostomy for their child is difficult to comprehend. In this chapter I discuss the ramifications of different constructions of feeding interventions for parents and their children. I argue that parental anxieties around feeding technologies reflect an ambivalence that the potential for change/transformation generates in terms of children's identities and relations with

others. A number of approaches or frameworks have been used to theorise difference. Many of these, informed by linguistics, anthropology and psychoanalysis, tend to naturalise difference and suggest inevitability. That is, symbolic boundaries are seen as essential to the order and stability of all cultures (Hall, 2001). According to these theories, when things are out of position the symbolic order is threatened and cultures respond by trying to recoup or normalise the object – a form of social control (Scambler, 2004).

I draw on resources from cultural theory, in particular Kristeva's theory of abjection, as a counterpoint to medical and psychological constructions of children's feeding (see chapter 3). Emotions such as horror and disgust sit uneasily within the psychic economy and disrupt the rationalist, masculinist, body-machine metaphors which represent children's bodies as objects to be operated on and 'fixed'. I conclude by problematising the 'cultural turn' to bodily projects.

Writing the body in or out?

The Bionic man may no longer seem far-fetched given the explosion of technological innovations in recent years, giving rise to an increasing focus on bodily matters in the medical and social sciences (Williams, 2001). Williams suggests the role of biotechnology in transforming the body, reproductive technologies, genetic engineering and the associated ethical issues that arise with the introduction of these innovations are also responsible. Turner (1995:228) highlights a number of alternative influences, including feminism, both in wider society and the academy, anxieties about the impact of HIV and AIDS and other debilitating conditions, and the significance of 'lifestyle aesthetics' in consumer culture. The body is also topical because of the way different theories either reinforce, or deconstruct, the distinctions between mind and body, structure and agency and nature and culture (Shilling, 1997). Gatens, (1996) suggests these ways of thinking polarise and limit how we conceptualise the body and are commonly associated with Cartesian dualism. This dualism has informed the 'legal subject' – constructed as the autonomous, rational, and hence disembodied, male (Bridgeman, 2000).

The mind/body split has implications for children in relation to decisions about health care treatments affecting their bodies. Where the competency of a child to make decisions is questioned, the law intervenes on their behalf:

The law is primarily concerned with the mind of its subject – with questions of capacity, intention, consent -whilst, at the same time, extending to regulate the body (Bridgeman, 2000:210).

There is a parallel with women's bodies in relation to enforced sterilisation, abortion, Caesarian births and contraception; areas where the law intervenes and regulates women's bodies. Theories of the body, then, are of concern to feminists because of the constraining effects of body discourses underpinned by patriarchal codes which dominate women's bodies and experiences (Lyon, 1999). For example, discourses of the biological body have been used to discriminate against women in education, employment and political life (Weedon, 1989). Women's bodies have also been exploited by a male dominated science and medical profession (Stanworth, 1987). Gatens, (1996) observes that despite women's attempts to gain autonomy over their bodies (witness various campaigns for safe and effective contraception and abortion facilities), feminists have failed to adequately theorise the relationship between women's bodies and the state. The privileging of the body sits uncomfortably with many feminists and disability activists, not least because of the concern that this represents a move towards a biological determinism which has social and economic effects for those deemed to have 'inferior' bodies.

The metaphor of 'the cyborg', 'a hybrid of machine and organism' (Haraway, 1990:191), has been embraced for its liberatory potential because of its 'leaky' boundaries which transgress the borders between 'human, organism and machine' (Lykke and Braidotti, 1996:5). Without history or gender the cyborg offers, 'possibilities for escaping the limitations of gender and other stereotypes' allowing women to 're-code the self and the body' (Valentine, 2001:59; Haraway, 1990). In this chapter I argue that gastrostomy feeding technologies also involve a recoding of the body but that this cannot exist in isolation of the material circumstances which shape mother, child and family relationships. Parental accounts are analysed in terms of

complex cultural-political overdeterminations between discourses of mothering, children's rights and normative child development.

Parental constructions of feeding technologies

The words 'not normal' or 'unnatural' were used in parental constructions of feeding technologies. Women's constructions of gastrostomy distinguished between the gastrostomy tube as an object (the gastrostomy-body interface), the stoma (the hole created in the stomach where the tube is inserted) and the actual practice of feeding a child by tube. Parental concerns tended to focus on the extent to which a feeding tube would transform children and render them 'other', or transform their relationship with their child which they constituted through feeding (as discussed in previous chapters). Different kinds of feeding technologies were constructed along the dimensions of temporary-permanent, reversible-irreversible, interior-exterior. The extent to which parents perceived the gastrostomy tube to be permanent informed constructions of feeding technologies and their role in transmuting the child. Parents' constructions of gastrostomy feeding included a discourse of disgust and fear as suggested by the words 'scary' and 'disgusting'.

Gastrostomy as an object

Graham's mother initially constructed the gastrostomy as something not normal and as an undesirable object 'hanging out' of the child's body. She later moderated her view by conceding some beneficial aspects to tube feeding in terms of the child's comfort. However, the tube was generally constructed as something 'horrendous' and 'scary':

It was like the first initial reaction was 'no, no way' because you wouldn't want that hanging out of your child's body, and it's just not normal is it, it's not, but when you think about it and you think about the good points and the bad points and you weigh things up and it's for Graham's comfort and his benefit, then you get a different aspect on it, when you speak to, you get more information on things. But it's scary, you see something like that and you see a picture of it and you think, oh my God, like that's horrendous, but it is scary. [Graham's mother, 1/2]

In the next extract the gastrostomy is constructed as a 'foreign object' preventing others from physical contact with Graham. The fear that physical contact might disturb the gastrostomy, and cause pain, served to further the construction of Graham as vulnerable and fragile:

Because it's a foreign object innit really, it's not something, like picking the child up. I mean I'll get used to it, my husband will get used to it, but someone that doesn't see Graham that often will be, 'no, I don't want to touch him cos of hurting him', and they're like that with him anyway so something like that will just make sort of that worse. [Graham's mother, 1/2]

Graham's mother also spoke of her growing sense of isolation as a result of loss of contact with friends and family. She attributed their avoidance to Graham's disability. The gastrostomy is constructed as something that would deter others from social contact.

He, when I first mentioned the tube to him [husband], I was against it when we first spoke about it cos I thought it's not natural, but when we spoke to the consultant and she said perhaps we just feed him overnight, we get him fed overnight, boost him up, then I could see the sense in that, I thought that's an excellent idea, cos I didn't want him being fed during the day through it. Um, but my husband was, he said it's going against nature. But I, I do see it like that in a way, but then I see it in the way that Graham needs more than what he's getting but he can't physically drink or eat more than what he's getting... He doesn't really say a great deal, but I do think it's going against nature, it's just medical, really. [Graham's mother, 1/2]

In the above extract Graham's mother drew on a naturalised discourse in her construction of the gastrostomy. Her partner similarly constructed the gastrostomy as 'going against nature'. They therefore constructed a dualism between nature and medicine. However the mother acknowledged that Graham needed more food than he was physically able to eat or drink, which presumably was his natural state. Graham's parents were then faced with the prospect of going against nature in order to sustain the child. The gastrostomy was constructed as advantageous when it functioned to 'boost up' Graham.

Ricki's mother also constructed the gastrostomy as an 'alien' object inserted into the child and as something not 'natural' –'it's not a thing God has given to him'. The tube was contrasted with the 'normal' attributes that a child is born with such as eyes, ears and a nose. Here medicine is constructed as interfering with nature through the act of inserting a gastrostomy. For Ricki's mother, the actual surgical procedure was also represented as being qualitatively different to previous operations where things had been 'taken out', for example cataracts, as opposed to an object being 'put into' the child's body:

Because this gastrostomy is a tube which is going to be placed in your child's stomach and it's not a thing that God has given to him, like when he was born he was born with eyes, ears, nose and everything, but this gastrostomy tube was not given by God, and so when this is a human being doing it to another human being, putting an object, well that's the way I saw it at the beginning, it was a thing, a piece of tube that's going to be put in by a human being, God never made it. [Ricki's mother, 1/2]

Anxieties about medical interference in nature were apparent in Ricki's mothers comment that the 'gastrostomy was not given by God', rather it was a 'human being doing it to another human being' and reflected an appeal to a higher voice of authority, that of a deity. Here she drew on a pre-Enlightenment discourse. The Enlightenment was characterised by a movement toward science and away from traditional sources of authority, particularly from religion as an arbiter of knowledge (Burman, 1994a). By drawing on a pre-Enlightenment discourse Ricki's mother challenges the primacy of medicine as an expert knowledge and its attempts to dominate nature. As William's (1997:1042) states, medicine is:

A modernist enterprise steeped in scientific tradition in which truth, order and progress are seen as paramount virtues. Seen in this light, current developments in medical technology represent a further extension of modernist imperatives centred on rational control and the domination of nature.

'So he'll be Ricki again': temporality and transformation

In the following account Ricki's mother constructed the gastrostomy tube in terms of its transformatory capacity relative to a nasogastric tube. Her account constructed a dualism between the temporary-permanent aspects of tubes:

Yeah. His father, Ricki's dad, in the beginning like me he thought, he didn't want to hear about another operation at that time as well and especially when, a few operations that he has had done things were being taken out from him, like cataracts or when stitches were being removed, but this is an operation that's going to be a tube going to be put down in his stomach and it's going to be connected to him and thinking of that sort of upset us, oh Ricki's going to be fed from a tube, or something is going to be stuck to his stomach. Because the tube in his nose you can put it in and out, some days he'll have it in his nose and some days he won't, so he'll be just Ricki again, but when he has the, at that time we thought when he has the tube in his stomach it's going to be something that's going to be always attached to him and we were finding that bit a bit hard as well, of something that's going to be in his stomach. [Ricki's, mother 1/2]

The temporary aspect of the nasogastric tube (i.e. it can be removed) serves to normalise the child - 'he'll just be Ricki again' - whereas a gastrostomy tube 'permanently' attached to a child's stomach, is constructed as transforming the child; he won't be Ricki. The tube is constructed as something that will transform the child's identity as recognised by others, especially his parents.

In contrast to Ricki's mother, who saw the nasogastric tube as temporary, Adam's mother constructed the nasogastric tube almost in terms of a fixed attribute of the child given that Adam's need for a feeding tube was firmly established shortly after his birth. The tube was therefore constructed as a part of Adam:

So the tube [NG] was never, it was never discussed, that it was just there and that's how we fed him and nobody really said, well this is going to be here forever and ever. It wasn't until like we went to a paediatrician and had a check-up I think. So it was never, the thought was never put into us, you know, how do you feel about it, it was there and that was it. It was there and it just stayed. So it was just like part of him really, we never really questioned it. [Adam's mother, 1/2]

From this account it is clear that the decision to feed by tube was taken out of the parent's hands given there was no alternative way of feeding. Parental perceptions of choice about gastrostomy feeding therefore may well have been framed by whether they felt they had any input to the initial decision to feed their child nasogastrically. For many parents this decision may have been removed. For example, eight of the families interviewed reported that their child had been nasogastrically fed since birth. These different reference points are important when asking families whether they had made

the right decision for their child to have a gastrostomy (discussed in chapter 5). That a nasogastric tube can be construed as an attribute of the child, despite the fact that it can be removed, was clear from Nicki's mother's account, where she conveyed her sense of panic that her daughter would 'starve' when she accidentally pulled the tube out:

She um ... that [NG tube] was put in as a kind of emergency measure to get us over Christmas. It actually, funnily enough, I was feeding her one night and as I put her down back into the bed my elbow caught on the plaster and it pulled it right out, and she didn't actually whimper or anything and I thought oh God, because there's this feeling you get, once you've got the tube in like (sharp intake of breath) she's going to starve, she's going to starve and I sort of forgot that of course she could still probably try and take some by mouth. But I was saying 'Oh quick we've got to get her to hospital.' And [name of husband] said 'No hang on a minute, just try her with a bottle.' Anyway she just took back to bottle and solid instantly and was absolutely fine, so we left it. [Nicki's mother, 1/2]

The temporary/permanent distinction was also rehearsed by professionals who differed in their view of whether the gastrostomy could be removed at some point in the future as circumstances dictated. The disagreements were also gendered. The surgeons were more cavalier in their approach to the removal of the gastrostomy, suggesting that if parents were unhappy with it, or if the child's oral feeding improved, the gastrostomy could be removed. Conversely, the speech and language therapists were more inclined to emphasise gastrostomy feeding as part of the long term feeding management of children. Normalisation was not necessarily an imperative therefore. However, the possibility (or deception) that the gastrostomy may only be needed as a short term measure was reassuring to parents and, for some, made the decision a little easier.

In the same way comparisons were made between nasogastric tubes and gastrostomies in terms of permanency and naturalness, parents used similar constructions when talking about the antireflux procedure (discussed in chapter 3). In the interview with Edward's mother, the gastrostomy, although described as unnatural, was constructed as temporary because the tube could be removed. In contrast, the 'Nissens' was constructed as irreversible, and therefore a permanent intervention. The rearranging of internal organs - 'having your oesophagus pulled down and tied round' - was constructed as unnatural because it was irreversible:

Um, but we certainly didn't want the Nissen's that went with it, the fundoplication, cos that really did sound more like major surgery and it sounded a fairly nasty sort of a procedure, and something that was, whilst the tube isn't natural, I mean it's not natural having a tube in your tummy, somehow the, the, having your what oesophagus pulled down and your tummy tied round, all sounded totally sort of unnatural, and sort of irreversible. I mean his tube [g-tube] can be whipped out, you know what I mean, whereas the fundoplication certainly did seem like a very permanent situation, it sounded totally unnatural. So we were very keen to, we were keen to have the gastrostomy but to avoid the fundoplication which in fact is what happened. [Edward's mother, 1/1, post surgery]

Further, parents were often anxious to avoid the 'Nissens' because it represented a more serious operation, whereas the gastrostomy, despite significant morbidity, was often represented as a minor operation by clinicians.

Similarly, Joshi's parents reflected on the number and type of medical interventions he had experienced. The role of technological interventions (gastrostomy, shunt) were constructed as a process of 'othering' Joshi by rendering him special. Difference was constructed in terms of things the child would be prevented from experiencing, for example, not feeding orally or not being able to 'burp' or vomit, which were considered to be the natural prerogative of the child. These bodily processes of ingesting and expelling constituted normality and demarcated difference. Interfering with these processes was constructed as a denial of Joshi's right to a normal life:

I mean he's special in a sense already that he has a shunt and a gastrostomy and then we want to make him special anymore by well you can't be sick and you can't burp, and we want him to have, you know lead a normal life. So that's why I would have liked to have seen him without the Nissens and maybe like gone to the Nissens if it was really that bad, or if he was still vomiting a lot. [Joshi's father, 1/1 post-surgery]

Mutilated bodies – horror and disgust

Within medical discourse the word 'stoma' is used to refer to the cut or hole in the stomach where the gastrostomy is inserted. Families rarely used the term and may have only heard its usage in relation to the 'stoma nurse' - a designated nurse responsible for caring for children with gastrostomies, including the treatment of infections around the gastrostomy site.

Parental accounts constructed a difference between a nasogastric and gastrostomy tube in terms of a hole in the stomach artificially created to accommodate the gastrostomy. One parent compared it with a pre-existing hole, the nostril, which was a natural opening. In the following extract Zarra's mother recounted her disgust at seeing a child with a gastrostomy:

- M: So, I saw, it was a girl actually, I think she was 2 years when I saw her, and er yes, they showed me her tummy. It didn't seem alright to me, I was disgusted really. I didn't like it. Er, I saw another family, that was my counsellor who arranged it for me, so, er it was a mum again, and her daughter, and they came over here to my place and, it didn't make me really decide to go ahead with the gastrostomy. It was just, it's time that's made me make the decision. Time and er no more hope maybe.
- G: What was it about the gastrostomy that you found so difficult, what, can you remember?
- M: Just, the look of it (laughs) just that thing in there, in the stomach, yes, that was one of the things, plus it was a major operation and since we had the history we tried the NG tube I just was thinking to myself as I told you, even the NG tube was lots of trouble so how about a major operation, that was another thing. Sorry..
- G: Did you see the families feed with the gastrostomy, did they show you? No?
- M: No, they just explained to me, they explained. (laughs) Mmm.
- G: Can you say what it was about the look of it that, that you didn't like?
- F: Well it's a hole in the stomach, it's a hole (laughs). It's a hole in the stomach. It's a hole in the stomach. [Zarra's mother, 1/1]

Although the mother raised concerns about the operation and issues around tube management, an aesthetic consideration appeared to underlie her anxiety about the tube ('just the look of that thing in the stomach'; and the 'hole') which aroused feelings of disgust.

A number of authors have developed Kristeva's notion of 'abjection' as an explanatory framework for the emotions of horror and disgust and the compulsion to look away, to account for how people demarcate difference between self and other (Kristeva, 1982; Creed, 1993; Gross, 1990; Johnston, 2002; Sibley 1995). Taking object relations theory as its starting point, Sibley (1995) suggests that contradictory feelings arise as a result of the baby's experiences of the mother as a good or bad object in terms of her ability to satisfy the child's desires. 'Aversion and desire, repulsion and attraction, play

against each other in defining the border which gives the self identity and, importantly, these opposing feelings are transferred to others during childhood' (Sibley, 1995:126). These ambivalent feelings are then displaced onto those seen as different.

Gross (1990:86-89) distinguishes different types of abjections which have resulted in taboos and threaten the body's boundaries with the intrusion of the impure, including 'food, waste, and the signs of sexual difference'. People's reaction to these abjects is embodied in the form of disgust which, in its extremes, includes vomiting and retching (the very symptoms children with feeding difficulties experience in relation to food). The waste produced by bodies, for example spit, semen, and excrement, generates abjection because waste demarcates the body's boundaries from what is inside and outside and from what is clean and unclean. The urge to separate the pure from the impure results in the need to expel the abject. The abject therefore is what threatens identity (Johnston, 2002:85).

Adam's mother also constructed the gastrostomy tube as something not aesthetically appealing: 'I'm not keen at looking at it', in particular the 'tiny hole' in 'the belly'. Again she constructed the nasogastric tube as an attribute of the child relative to the gastrostomy as something 'new' that the child has had 'put in':

I've seen, I've looked at it [gastrostomy], I'm not too keen at looking at it, I'm not very good. Whereas the tube [nasogastric] was always there, it was part of him, this is, because this [gastrostomy] is something that he's had put in and it's more new, I'm a bit squeamish about it at the moment but hopefully once I get used to it they reckon that it's just, be like, a lot easier than the gastronasal tube and I'll find it a piece of cake. But I wasn't, I'm not, I wasn't looking forward to this part of it. Seeing the little tiny hole in his belly. [Adam's mother, 1/2]

Another mother suggested people would be disgusted at the prospect of having to feed a child through a hole in the tummy:

'some people like I said, won't accept the fact, have their child feeding using a hole in the tummy, they find it like it's disgusting or something'. [Ahmed's mother, 2/2]

In the next extract Ricki's mother recounted her experience of seeing a child's stomach following an antireflux procedure. The procedure had left an abdominal scar which was described as big and frightening on a small child. Conversely, the gastrostomy was described in less threatening terms, as small, and something the mother liked – 'I saw the button, I liked the button'. The gastrostomy was constructed as a more localised intervention, 'a slight cut' compared to the 'big deep cut' of the Nissens involving the child's chest and stomach:

But when I saw her gastrostomy she's got, the girls got the Nissens operation done with it and when I saw the button, I liked the button, it was just stuck to her stomach, it was a really small little button, but then when I saw the Nissens cut she said that's because she asked the doctor because sometimes her daughter vomits and the doctor then did something to the muscle in the stomach, tightened it or something. When I saw that cut then I felt a bit scared, I thought it was really big, and well I saw the gastrostomy tube and I saw the Nissens cut and I felt a bit ... um ... I felt um ... I felt scared, really scared, yeah really frightened at what I saw a little child has got such a big, deep cut on her chest and her stomach. Her stomach I couldn't see, it was just a slight little cut and then there was a button, but that cut, what they put for the Nissens was really big and I felt scared when I saw that and then I thought, I said to my husband that we shouldn't have, he went as well, I said to him we shouldn't have gone to see the child because it made us so frightened for the part, we were frightened for one week of what's going to happen to Ricki during the operation, what are they going to do, how's the cut going to look, how's his stomach going to look.
[Ricki's mother, 1/2]

In the following extract, Garry's mother compared the prospect of Garry having a Nissens and gastrostomy to a previous operation on his hips. Her fear of the Nissens operation related to the involvement of 'organs' and a 'delicate part of the body'-the stomach and nerves - suggesting a construction of the Nissens along an internal/external dimension:

- G: But you didn't feel like that with the hip operation?
M: No, because it was here, it's not the stomach, you're not going to get onto any of the organs, it's nothing inside here, and I think that's what frightens me more than anything else, because it's to do with a delicate part of the body which is the stomach, and that is what um, that is what frightens me, pulling the nerves.
[Garry's mother, 1/2]

Carol's father described himself as 'squeamish' when faced with feeding tubes. The state of being squeamish is induced by watching operations on TV, looking at [medical]

pictures in magazines, watching someone insert a nasogastric tube in his daughter's nose, or the act of suctioning Carol. The construction of himself as squeamish serves to exonerate him from carrying out certain caring tasks that produce the effect. The mother's laughter serves to position her outside of the category of the 'squeamish'. Her tone was one of gentle mockery when she told me her husband had 'never even suctioned' Carol. The emphasis on the word 'even' is suggestive of a task fundamental to Carol's daily care. Her emphasis suggests an element of incredulity at her partner's inability to carry out the task:

- G: What was the thing that you were saying about the tubes, that you were sort of unhappy about?
F: Oh, I'm squeamish about everything, I can't watch an operation on the TV.
M: laughs
F: Or see the pictures in a magazine, you know when they pull people ... to me, I suppose, I'm just really squeamish about things like that. I don't even like it when ...
M: He's not even suctioned her, have you, you don't even suction her?
F: No. I don't even like it, I can't even watch it when they put the tube down her nose. When one of the ladies said you have to test it yourself when you're a nurse, she said, I used to do it - oh God! (laughs) no, I'm just terrible, I can't stand anything like that, so that's probably why. [Carol's parents, 1/2]

Gross (1990:88) drawing on the work of Lacan, suggests erogenous zones are defined in relation to 'spaces' which demarcate the boundaries between the inside and outside of the body, for example, ears, mouth and nose. These sites define what is inside the body, and therefore part of the person (subject), and what is outside the body, and therefore constitutes an object (other). The body therefore is very much implicated in psychic formation.

The linking of the inside and outside of the body is apparent from parental accounts of complications in the follow-up interviews, where children experienced an infection at the site of the gastrostomy. This next extract with Cathy's mother illustrated the confusion around the nature of the material leaking from the gastrostomy:

I was hysterical, absolutely hysterical, and I was 'I don't know what it is, what's happening, it's gone all black' so I rang the nurse and she came out and she said it was overgranulating. And um, where I've been cleaning it, she was obviously leaking some gastric fluids which was causing it to redden, but it wasn't

actually, it was this infection that was on the inside, I couldn't get in because it was one [gastrostomy tube] that you couldn't get out of the tummy, it was stuck in the tummy, and there was that. And obviously then I experienced um, um, when Cathy wasn't well, and when I aspirated back I was drawing back blood, where she'd refluxed and busted a little vessel and so she bled inside so when I aspirated back, it's called grind coffee, coffee something or other, the colour of it, I was getting back something like lumps of blood which panicked me as well.
[Cathy's mother, 1/2]

Here her sense of panic is conveyed at the sight of the interior (blood and gastric fluids) leaking to the exterior. The uncertainty over the exact nature of the leaking material, whether food or waste, threatens the food/waste dichotomy. Gross (1990:91) expanding on Kristeva, suggests corporeal waste is 'symptomatic of our cultural inability to accept the body's materiality, its limits, its natural cycles and its mortality'. She goes on to suggest that faeces, in signifying the opposition between the clean and the unclean, 'draws on the distinction between the body's inside and its outside'.

In Cathy's mother's account the inside/outside dichotomy is deconstructed through the gastrostomy. Although the account Cathy's mother recounted is atypical (and chosen explicitly for the purpose of illustration), gastrostomy tube/site related complications are common; for example, the results of the clinical evaluation suggested that 43.2% (32/74) of children experienced 'infections' - oozing, redness, or leakage. The complications, although considered 'minor', and are usually treated with topical creams and antibiotics; cause families a great deal of distress in terms of the aesthetical appearance, the discomfort children experience, and the need to learn new nursing procedures in caring for the gastrostomy site.

Interestingly, there were also examples of professional abjection in a wide variety of contexts. Clinicians averted their gaze while watching a video of a mother feeding her child. The abject lay in the (assumed) knowledge that the child was aspirating and the frenetic attempts by the mother to feed her, which would not have met the standards of sensitive mothering. Similarly, I remember 'looking away' while watching a mother brush her son's teeth while he grimaced. The abject lay in the (assumed) knowledge that children are often hypersensitive around the mouth and that the rigorous brushing of teeth involved coercion and discomfort. Not only is disgust framed by culture but local knowledges also play a role.

Probyn (2000:125) notes the way shame and disgust have been erased within identity politics, partly because of the revivalist 'anything goes' approach to the body and the politics of pride:

From the shadows of shame, the politics of pride has extended these efforts to unequivocally posit that there is nothing to be ashamed of if your body is gay, black or disabled, fat or old.

Drawing on her own experiences of anorexia, she makes a connection between eating, disgust and shame. She asserts that both fat (obese) and thin (anorexic) bodies provoke disgust and shame. Disgust, she claims, has 'evolved to protect' humans from coming 'too close' to the object for fear of being engulfed by it and of being 'brought into intimate contact with what is considered to be another category of being'. She argues the shame produced at one's own feelings of disgust at the sight of another's body, prompts avoidance (Probyn, 2000:131;134, quotes Tomkins, 1991). However, this does not account for why particular bodies should necessarily produce disgust.

Parental reactions when confronted with images of the stoma, sometimes oozing or infected, and tubes and scars, can be explained in terms of the way such images challenge normative constructions of children's bodies which culturally signify purity and perfection. It may seem far-fetched to draw on a symbolic framework to account for parental unease about particular aspects of feeding interventions, but there is something that resonates with the concept of corporeal boundaries in the families' accounts.

Whereas bodily orifices (mouth, ears and eyes) are eroticised, the stoma/gastrostomy represents ambivalence because it displaces the mouth as the site where feeding and, potentially, pleasure take place. Both the stoma and the gastrostomy, constructed as medical and artificial but also associated with feeding, itself an erotic activity, represent the ambiguity, the abject. A medical intervention involving tubes, holes and scarring serves to de-eroticise the child's body, denying pleasure to both parents and, it is assumed, the child. Images of feeding technologies create a tension as they transgress boundaries positioned at the interface of what is inside and outside the body; what is potentially lifesaving may also incur the risk of pain or perhaps death, and what could

offer the potential for 'normalising' a child through health and weight-gains, may 'other' the child by making her different. These conflicts may, in part, explain why some parents found the decision to have a gastrostomy inserted in their child so difficult. As Flax, (1990:11) states: 'ambivalence is an appropriate response to an inherently conflictual situation'.

The idea that revulsion may be gendered is discussed by Poole and Isaacs (1997), who cite Ungerson (1983). Ungerson discusses whether a taboo system exists in relation to the management of bodily fluids, given the gendered division of domestic labour and caring. She suggests that intimate caring is designated as women's work because women are already polluted with menstruation and childbirth. Conversely, Poole and Isaacs offer a materialist perspective on the concept of revulsion: managing vomit, they suggest, is unpleasant, but men are more able to refuse to do demeaning work by virtue of their power. However, revulsion is not only socially, culturally, and historically variable, but gendered, raced and classed, as more carers within institutionalised settings like the NHS are likely to be migrant workers from poor resourced countries on which the NHS depends. Some people may find disposing of bodily waste unpleasant but are not in a position to choose how they earn a living and so learn to deal with their revulsion. Indeed the question of how mothers deal with their revulsion is pertinent here. Women who are unable to mother in the conventional sense may over-adjust and displace their mothering and their abjection onto the role of carer. Prolonged periods of time spent feeding, cleaning up food spillage and vomit, suctioning, carrying out physiotherapy and toileting, are not usually associated with everyday child care activities beyond a certain age. I discuss this aspect further in the final chapter.

Conclusion

In this chapter I have looked at the way parents construct feeding technologies as phenomena that transform their child and make them different or other. This transformation is not always interpreted negatively as the ability to transform the child from sick to well, from poorly nourished to well nourished, was seen as a major benefit of the procedure. However, for families, the decision was rarely that straightforward

and their accounts of feeding technologies reflected an ambivalence that the potential for change held. In the next chapter I discuss an example where the prospect of a child gaining weight created parental anxiety, suggesting that potentially 'positive' transformations may have negative effects.

I have explored the concept of disgust in relation to Kristeva's theory of abjection. Notions of horror and disgust rarely feature in relation to the topic of the body in the social and medical sciences, which is perhaps surprising given the availability and uptake of cosmetic surgery designed to alter and achieve the perfect body. The emphasis on aesthetics in contemporary culture has perhaps sanitised the more 'unsavoury' aspects associated with body projects and transformation - blood, pain, knives, needles, flesh and scarring. However, these issues were very much at the fore of parental concerns, perhaps because gastrostomy surgery is not a cosmetic intervention, and because parents were making the decision on behalf of their child.

If the body is infused with, and colonised by, consumer culture, does this simply mean that 'postmodern bodies and sexual identities are the product of freely chosen consumer decisions'? (Lyon, 1999:83). Piercing and decorating the body can make a statement, but what kind of statement does a gastrostomy make and can we simply redefine tubes drawing on the revivalist discourse of the body? As Scambler (2004) states, norms of identity are influenced 'via the aestheticization -one aspect of the (hyper-) commodification -of the body'. Gastrostomies, leaking stoma, scars and vomit, threaten us with 'the intrusion of the ugly or tasteless'. Gastrostomies neither 'look nor feel good'.

Whereas some feminists have celebrated the mythical cyborg identity (Haraway, 1990), there may be limits to its potential as a radical force, and I am thinking of scientific developments in infertility research where eggs have been produced from aborted fetuses ('Prospect of babies from unborn mothers'. *The Guardian*, 1 July 2003). Would the 'unborn mother' referred to in the article qualify as a cyborg and, if so, what are the implications of this 'blending of technology and motherhood' for women and feminists in relation to discourses of fertility (Sourbut, 1996:238)?

The crafting of the perfect body as a cultural imperative, and the personal responsibility of the owner to achieve this, takes on a deeper resonance for those with bodies that don't meet the cultural norms of perfection, particularly those with disabilities²⁵. Operating on the eyes of children with Down's syndrome to make them look less disabled, for example, fails to address why disability is unacceptable in the first place. Further, privately funded cosmetic operations stand in stark contrast to the way disability and age are used to ration health care in the NHS (Disability Rights Commission, 2003).

Morell (2002:72) quotes Wendell (1996) on the negative stereotypes and stigma associated with the 'rejected' body, used to refer to those 'aspects of bodily life (such as illness, disability, weakness, and dying), bodily appearance (usually deviations from the cultural ideals of the body), and bodily experience (including most forms of bodily suffering) that are feared, ignored, despised, and/or rejected in a society and its culture'. Yet bodily suffering has been used as a marketing strategy for the fashion industry, and I am thinking about the anorexic looking models on the catwalk, with their black eyes, who not only looked emaciated but as if they had been physically abused.

How is it that a shamed body, an image of a victim in a Belson concentration camp for example, with hollowed out eyes, produces shame, horror and disgust, but place a similar image of a woman on a catwalk and she is transformed into an object of desire? This example perhaps illustrates the 'instability' of particular images which are always being re-worked to produce different effects in different contexts. However, they also serve to highlight, and problematise, the dangers of privileging the cultural and aesthetic postmodern body, taken out of context of the material and economic factors, that discursively reproduce the body. Similarly, although every society may have its own abject, this does not satisfactorily explain abject reactions toward groups of people who are othered and the role of gender, race and class in constituting the abject.

I have already alluded to the possibility that bodies produce various effects across different economic, class, raced and cultural contexts, suggesting there may be other

²⁵ Ironically, perhaps, the research on embryos mentioned in the previous paragraph was carried out on fetuses aborted due to malformations.

discourses at play which inform our understanding of parental ambivalence toward feeding technologies. I continue the discussion of shame and stigma in relation to children's feeding and disability in the next chapter.

10. Challenging stigmas

'She finds it a bit embarrassing you know she doesn't like to be different' [Judy's mother]

Introduction

In this chapter I continue to explore difference in relation to theories of deviance and stigma. I argue that not only do theories of stigma individualise disability, but they also fail to adequately theorise the effects of race, class and gender. In particular, stigma theories fail to acknowledge the link between women and state and women's role as transmitters of cultural identity through the bearing and rearing of children (Anthias and Yuval-Davis, 1989:7). Yuval-Davis (1997:45) suggests: 'Women are associated in the collective imagination with children and therefore with the collective, as well as the familial, future'. As such, gender relations lie at the heart of cultural constructions of social identities and collectivities. I explore women's constructions of feeding technologies and the impact on their children. I then examine children's experiences of tubes as represented by their parents, and I end with a discussion of some of the limitations of stigma theory.

Constructions of stigma

In response to the question of how parents and children might benefit from a gastrostomy, mothers of children with nasogastric tubes spoke of the highly visible and stigmatising effects of NG tubes which attracted unwanted public attention. The view that a gastrostomy would be hidden, and therefore represented a more discreet form of feeding, was seen as an advantage of the procedure. As such, for some families the gastrostomy served to 'normalise' this aspect of the child. 'Facial disfigurement', caused in part by the NG tube and the surgical tape needed to keep the tube in place, is a very social phenomenon, rendering the child's face public property and prompting people to stare and question. Given the young age and small size of the children, many of whom were still in buggies rather than wheel chairs, it was not always apparent that

the child had a disability. As many parents commented, if it wasn't for the nasogastric tube signalling a problem, no one would know that there was anything 'wrong' with their child. Douglas, et al., (1998) also found mothers of children requiring a NG tube because of renal failure reported a high level of 'social difficulty' because of the visibility of the NG tube.

Parents often referred to props or cues as signifiers of disability –nasogastric tubes, wheelchairs, feeding in public where a child coughs, chokes, vomits and for some the actual practice of feeding by tube. Without these 'stigma symbols' (Goffman, 1990:59) the child's disability would not have been apparent:

And then you've got people looking at him seeing why he's, you know people ask why as he got a tube, and then, I won't have all that now. He'll look like a normal baby (laughs) for a while. [Adam's mother, 1/2]

There's no tube sticking on her face, her face has recovered from all the tapes, and um, yeah she looks normal when she goes out, yep. [Jane's mother, 2/2]

Both Adam and Jane's mother constructed the removal of the NG tube away from the child's face as a normalising force in terms of appearance. In these examples the NG tube signified disability.

The gastrostomy is much more discreet. I felt with the nasogastric tube it was just, it drew so much attention to Garry and to me and I don't like it. Basically. So people can see that he's disabled, but they're not looking more at him, because he's got a tube in his nose, and that's the difference now. [Garry's mother, 2/2]

Goffman (1963) was one of the main authors to discuss the effects of stigma in the context of daily, social interaction. Stigma has come to be used to refer to those attributes that signal difference in relation to an assumed norm and are usually negatively appraised. Where negative information about a person comes to light during social interaction, a discrepancy between their 'virtual identity' – a form of impression management – and their 'actual identity', renders them 'discounted' or stigmatised (Goffman,1990:13). Scambler (2004) describes this as an offence committed against the norms of the social order. Goffman suggested that stigma can have a deeply

'discrediting' effect which 'spoils' a person's social identity, or sense of self. People who are 'discredited' are those whose stigma is visibly apparent or 'known about', while the 'discreditable' are those whose stigma is only occasionally apparent as in the case of epilepsy (Scambler, 1997; Scambler and Hopkins, 1986) where people are able to 'pass as normal' until exposed by a seizure or verbal disclosure. Whereas the main problem for the discredited is the 'management of tension' in social interaction, for the discreditable, the issue is one of information management with respect to the stigmatising condition (Goffman, 1990:57).

Ricki's mother constructed people's negative reactions to the NG tube as a barrier to going out. For her the tube rendered the family exposed to the outside world in conveying privileged information not only about feeding, but about the family's circumstances, and perhaps attests to the way disability is privatised within the institution of the family and the home. The mother constructed the gastrostomy tube not only as something that would conceal Ricki's feeding difficulty, but the family's experience – what happened to them, what they went through – would be hidden:

So this tube is really sort of, in a way has made our life a bit difficult to go out and because I think when I take him out people stare so much, it's just um I can't take him out then as much as we did and as much as we'd like him to go out with us. So I think when the gastrostomy is done, I'm coming to the point, when the gastrostomy is done that will be hidden and nobody will know what went through, what happened to us, what's Ricki's feeding is like, it will be all hidden so. But my husband thinks that, his dad thinks that it doesn't matter if people look at you like that, it's just people are looking, they have to look to understand, but I think OK they can look to understand but not look, look, look, all the time. [Ricki's mother, 1/2]

Goffman (1990:41) used the term 'courtesy stigma' to describe the way stigma extends to others - 'the wise' - by virtue of their association and insider perspective. This was apparent in parental accounts when they spoke of the perceived negative reactions of others, usually in the form of hostile staring or unwelcome questioning about the tube. In these examples parents were, 'obliged to share some of the discredit of the stigmatised person' by virtue of their affiliation (Goffman, 1990:43). For Ricki's mother, the substitution of the nasogastric tube with a gastrostomy would allow Ricki, and the family, to 'pass as normal', from the category of the 'discredited' (the visible

NG tube is removed) to one of the 'discreditable' (the gastrostomy tube is hidden under the child's clothing).

Garry's mother acknowledged that although people could see that Garry was disabled (he sits in a wheel chair which would presumably serve to 'discredit' him), the substitution of the nasogastric tube with a gastrostomy signified that Garry would no longer be discredited, but discreditable, in relation to feeding. Garry is therefore simultaneously discredited and discreditable, and only discreditable when fed by the gastrostomy tube. This suggests the salience of stigma cues and the ability to 'cover' and 'pass' are largely context dependent.

Courtesy stigma was apparent in the mother's comments, 'I just don't want to draw that attention to myself':

Cos the first time I fed him with a bolus feed, you know, through the nasogastric tube um in a restaurant, and people were just staring, and it's that kind of thing which I felt just gave a negativity. He's not bothered cos he's not aware, but I think it's just me, I just don't want to draw that attention to myself.
[Garry's mother, 2/2].

However the concept of courtesy stigma fails to explain why women feel shame in relation to their disabled child. In accounting for parental anxieties about feeding it may be useful to draw on the distinction between 'felt' and 'enacted' stigma (Scambler and Hopkins, 1986). Enacted stigma refers to the actual experience of overt discrimination or rejection by others. For example, one mother mentioned how a customer in a pizza restaurant complained to the management about her feeding her child with a gastrostomy (and the parallel with breastfeeding in public is worth noting). Conversely, felt stigma refers to the fear of discrimination, shame or rejection. So for example, some mothers would not even consider feeding in public places for fear of reproach. In Scambler and Hopkins' study of epilepsy they identified concealment (of the condition) as a coping mechanism: people rarely disclosed they had epilepsy for fear of discrimination or ridicule (felt stigma). However, when people were asked if they had experienced discrimination (enacted stigma) very few had. The authors concluded that the anticipation, or fear, of being discriminated against was particularly detrimental in its effects.

While providing a useful descriptive framework of parental coping and behaviour, the theory of felt and enacted stigma fails to theorise why women with disabled children should be discriminated against, or fear discrimination. I revisit this question in the section on 'deviant children/deviant mothers' later in this chapter. Reluctance to feed in public however was not totally driven by a fear of stigma, and mothers suggested a number of practical limitations, such as having to carry and sterilise the equipment, which presented an additional barrier. These difficulties were usually overcome with a little planning and organisation. The example serves to illustrate how women's use of public space is constrained by discourses of caring (Day, 2000).

There were other examples where feeding practices were constructed as unnatural. For example, Carol's mother did not want Carol to be continuously fed through a pump. Rather she wanted feeding by tube to correspond to mealtimes - breakfast, lunch and tea - perhaps to maintain family routines as well as oral feeding. Here the prospect of continuous feeding threatens to 'other' the child, although post-operatively the mother spoke of using the pump for a continuous overnight feed. So although parents reject the notion of continuous feeding during the day, they may consider it as an option for the night time:

I have seen one of the little girls in Carol's class is actually being fed all the time, 24 hours, so it's on a wheel chair pump and when I went up there (to hospital) I made a point of saying that I didn't want that. I want her to have some breakfast, lunch and tea, the same, and they said that would be okay, they would be able to do a bolus feed, and also to still feed her as well if we wanted to. [Carol's mother, 1/2]

The idea of rejecting or ignoring unwanted attention is also evident in parental accounts. For example, parents did tube-feed children in public places regardless of people's reactions. One mother spoke of her refusal to answer prying questions about her child, while Nicki's mother reframed people's prejudice, manifested in the form of avoidance, as something that created a welcome barrier against intrusive questioning. In Nicki's mother's account it was the practice of feeding with a gastrostomy tube that rendered Nicki discreditable, rather than the gastrostomy per se; but ironically this provided a space free from questioning and having to provide an explanation of why her child was fed by tube:

Feeding her out sometimes, I've now sort of sat out and fed her in cafés. People, I haven't had any comments which has been really nice. Funny, it's like put a sort of welcome barrier actually, in a way, cos I used to get a lot of comments before about 'how old is she?' and 'oh, isn't she small?' Whereas now I think people see there's something you know, going on with her, and they kind of leave me alone and it's really nice, it's different. [Nicki's mother, 2/2]

Garry's mother also suggested that other aspects of her child's physical appearance (his thinness) were potentially stigmatising. While she accepted her child was disabled, she did not accept that Garry had to 'look the part':

I feel that when you have a child that is looking ill, underweight, sick, it just projects negativity, and I can't work around that, and that is just my view basically, he's not suffering from cancer, he's not suffering from something that will cause him to look like that, and it's like I said to the speech and language therapist, that um not because they've got cerebral palsy means they have to look the part. And that is just my view on it, I don't see why these children can't be healthy. They don't have to be overweight, I appreciate what they're saying, I wouldn't want Gary to be overweight because he would be difficult to handle, but I don't think he should be cheated out of looking normal in that sense, and that's just my view. You know, and that's what I said to the Dr, if he looks skinny and lager, I said lager, that's skinny, that's Jamaican patois there. [Garry's mother, 1/2]

Looking ill (underweight, sick) was associated with having cancer and 'looking the part'. Images of suffering, illness and disability draw on cultural images of wasting and dependency. Adopting a psychoanalytical perspective to the cultural analysis of aid imagery, Burman (1994b:240) argues that children who do not conform to idealised images of childhood 'sit uneasily' within the psychic economy. Such images contravene normative expectations of children, sentimentalised as pure and innocent. Garry's mother equated thinness with ill health and sickness. Being thin not only signifies illness but also adds to the construction of Garry as a very disabled child, while looking healthy subverts this image. In drawing this distinction she affirms that a child can be disabled but healthy in appearance, which disrupts the conflation of illness with disability. The utterance: 'I don't think he should be cheated out of looking normal', again subverts the image of disability as fixed, 'natural' and inevitable. The gastrostomy provides an opportunity for 'normalisation'. The use of the word 'cheated' implies the right of the child to 'look normal'.

The use of the word 'lager' is distinctive and ascribes a special significance given its rare usage outside of the Jamaican community (i.e. in an interview with me, where she communicates a cultural norm which she assumes I do not know about). In clarifying the word's meaning (skinny/thin), and origin (Jamaican), Gary's mother is drawing on cultural identifications to give credence to its significance. The effect of the use of the word 'lager' serves to reproduce the 'other' of disability and race by drawing on the notion of dominant versus minoritised culture to mark difference. She again alluded to the role of culture in holding mothers directly responsible for the health of their children. A thin child draws moral opprobrium for a thin child equates with a neglectful, and poor mother. This may have a particular resonance within West Indian communities because of their experiences of deprivation (Helman, 1994). Here Garry's mother is drawing on a discourse that is both raced and classed. The shame of a thin child contrasts with the shame of a fat child; the former signifying poverty and neglect, while the latter also suggests neglect in failing to regulate the child's intake - in short, a double-bind.

Current concerns about obesity in the West, and in developing countries reflect anxieties about children's bodies. Children should be neither obese nor malnourished, neither fat nor thin; rather they must be 'just right'. However the notion of 'just right' is itself a specific historico-cultural construction. Although traditionally the scourge of a thin child was attributed to the 'feckless' poor for failing to appropriately manage their income and hence diet, rather than poverty per se, reports of middle class mothers placing their daughters on restricted diets in the US over fears of obesity implicate mothers of all classes in their child's dietary management. Thinness in children is also gendered and is more likely to be encouraged or condoned in girls, although the anorexic/malnourished body is likely to provoke disgust and shame (Probyn, 2000).

Women then become the guardians of the nation through the transmission of cultural codes which define how they should mother and regulate their children, positioning women as 'symbolic border guards' (Yuval-Davis, 1997). Their role as promoters of cultural practices demarcates who is inside and outside the culture. Gender relations are therefore central to discourses of the nation as women are 'constructed as the symbolic bearers of the collectivity's identity and honour' (Yuval-Davis 1997:45).

Similarly, Garry's mother demarcated difference (i.e. who was inside/outside the culture) through her child's body. While acknowledging that it was acceptable for a teenager to be thin, reflecting a construction of the autonomous individual who has the right to regulate and control her own food intake and body size, she constructed the responsibility for her child's weight and appearance as her own; this places women as the regulators of their children's bodies, ensuring they conform to an idealised norm which, as we have seen, is historically and culturally variable. Children's bodies that fail to conform reflect badly on women's parenting skills and render children outside the culture. This is apparent in cultures where female genital mutilation is practised, where women 'collude' in the regulation of girl's sexuality. Scambler (1998:120) notes the insidious aspects of patriarchal practices 'hidden in the ideological make-up of cultures' that render them difficult to dismantle.

In the following account Garry's mother again drew on a cultural discourse implicating women in the health of their children where women are stigmatised and held responsible for their child's thinness. The mother spoke about the stigma that would be 'forced' on her if her child were 'skin and bone'. Women are therefore implicated in the cultural and biological (re)production of a nation through their children (Yuval-Davis, 1997):

And this is one of the things, and one of the major factors that did it for me, if Gary was looking very thin, and when he looked very thin it made me very depressed. Because I know he's got a disability but if he's healthy-looking it takes away a bit of that disability, it's not looking all depressing. I can take him out and I don't have to feel, oh everyone's immediately going to stare at him because he's skin and bone. In my culture, if a child is skin and bone, they'll say, why haven't you fed him, you must feed him, you must make sure he's fed, never mind about what he doesn't want, you feed him. And that is what would be forced on me. And that's a real, it's a stigma thing in our culture, that your children must be healthy. [Garry's mother, 2/2]

Here the right of the child to choose what he wants conflicts with the mother's responsibility for ensuring an appropriate body shape and size. The appearance of children in conveying information about the severity of their condition was also alluded to by Nicki's mother, who commented on the difficulty of conveying the serious life-limiting nature of her child's illness because Nicki didn't look 'vegetable-like':

It's just the ongoing relentlessness of it and knowing it's not going to change, that's hard to convey to people. The day-in-day-outness of it all. So yeah if you saw me like as a snapshot now, yeah that's not a problem, just fed her, she's been sick but that's not totally out of the question. She's happy, you know it would seem oh no problem there, that's the thing that's hard to put across really. You know because she doesn't look absolutely awful, she's not puking all over the place and vegetable-like and, you know what I mean? [Nicki's mother, 1/2]

The significance of stigma cues in exposing or concealing a child's disability are therefore dependent on the social context. Whereas Goffman (1990:125) suggested the discreditable are faced with the task of managing (i.e. concealing) information about their stigma resulting in the 'adaptive technique' of 'covering', the reverse was true of Nicki where her 'public self' did not convey the fact she had a life-limiting condition.

Deviant children, deviant mothers

Scambler (2004) makes the distinction between stigma as an 'ontological deficit', where a person is viewed as unacceptably different because of some imperfection, and deviance, which implies a 'moral' deficit. In contemporary Britain, particular groups of people (e.g., asylum seekers and homeless people) are increasingly held responsible for their situation, and constructed as deviant. The rhetoric of individual blame masks the root causes of homelessness and the displacement of people through famine, war and global migration.

Gray (2002:735) quoting Goffman (1963), suggests people have a choice about whether they associate with deviant groups which is attributed to a 'moral failing'. As Gray (2002:736) rightly points out, given parents are morally and legally obliged to care for their children they cannot 'refuse the association' - there is no choice. However, this perhaps masks the gendered aspect of parental responsibility as men are more likely, and more able, to leave their wives with a (dis)abled child, rather than the reverse (Paskin, 1990).

In the case of disabled children they are not usually held responsible for their situation, although their mothers may be. In chapter 6, I discussed how child care manuals give

the impression that disability is something that can and should be avoided. Consequently, if a woman has a disabled child, she feels responsible and is blamed. (I discuss the issue of guilt and blame in chapter 11). Women may blame themselves for having a disabled child, and the recommendation of a gastrostomy further questions their ability to mother for having failed to establish feeding, as signified by their child's thinness and poor growth. Further, women are reminded of this when they come into contact with health professionals and their child is weighed.

Children's weights are compared to age-appropriate normative values based on non-disabled children, and dietetic advice is informed by these norms (Cole et al., 1998). Dominant medical constructions of disability view disability as a characteristic of the individual, that is, in terms of an illness or defect. Disability is constructed as an unnatural state because it is defined in relation to the able-bodied, and is therefore viewed in terms of a lack, or deficiency (Oliver, 1993). The idea of norms around feeding, growth and nutrition operate as a standard against which deviation or abnormality is marked. Not surprisingly, women felt guilt and blame when told their child was underweight and advised to increase their child's calorific intake. Women have to prove their parental competence in their interactions with professionals. The weighing sessions served invariably to undermine their competency. In the clinical evaluation, for example, some mothers refused to have their child weighed at the hospital. These acts of resistance, and sometimes mothers adopted more covert strategies of avoiding the weighing sessions by providing professionals with a verbal weight, served to protect them from professional rebuke. However, by refusing to conform to hospital procedures, this only served to confirm their deviance in the eyes of the professionals.

In the last chapter I spoke about parental anxieties in relation to bodily transformation and suggested that even potentially 'positive' changes may have negative effects. Whereas poor growth is considered a major indication for a gastrostomy, not all parents accepted that their child's weight was the main priority given the complexity of children's overall medical and social needs. As such, different views were expressed about the possibility or desirability of weight-gain. Parents and professionals alike expressed concerns that the child might become too heavy to handle if weight were

normalised. Carol's parents, for example, were worried that if Carol became too heavy to lift, carer support might be withdrawn because of a European ruling designed to protect workers from lifting heavy weights without the aid of specialised equipment installed in the home. The increased weight-gain that gastrostomy feeding can promote over a relatively short time period for some children may mean families are faced with these issues without being adequately prepared:

- M: And then he[the consultant] said, we've got to think about the weight that she's going to put on, whether we're going to be able to carry her because she's at home all the time, apart from when she goes to respite. And he was the only person, that, we'd thought of the weight but no-one else had mentioned that and that is a very important part of her life, because if she gets too big and we can't keep her at home then
- F: Because we can't, we've got nowhere, you know, we can't make a bedroom or anything downstairs, we're up and down the stairs all the time
- M: We'd be carrying her up and down the stairs, so I'd get help coming in twice a week ...
- M: Yeah, because of this new EC ruling about not lifting weights heavier than about 2.5 stone. We'll have to keep her just below two and a half stone[both laugh] otherwise all the help stops. [Carols' parents, 1/2]

This example is illuminating because it shows a complex interplay of rights. The child's right to achieve her growth potential is pitted against a health and safety concern aimed to protect the rights of workers and Carol's parent's rights to look after their child in their home with carer support. The gastrostomy appears to threaten these rights if Carol becomes too heavy.

One mother expressed her frustration about the dietetic advice she was receiving based on scientific norms and the conundrum of how much to feed a child 'genetically modified' not to grow. The discourse of genetic modification serves to exonerate her from responsibility for the child's poor growth (although in chapter 11, I demonstrate how she assumes responsibility for Nicki's growth):

I really felt this child wasn't growing ...if she's genetically modified not to grow then why am I stuffing food into her anyway. What is the right amount to give a child who's not going to grow rather than she should be eating this because she's this weight and she should be eating that. She's still eating as much as a newborn, you know and she's 15 months old. [Nicki's mother, 1/2]

I now turn to a discussion of the construction of children's experiences of feeding as mediated by their parents.

Constructions of children's experiences

The importance of children's views in assessing health outcomes is increasingly recognised (Dixon-Woods et al., 1999). However, claims about involving children need to be considered in the context of constructions of children as victims of adult protectionism (note the research ethics committee requirements that children should only be interviewed in the presence of their parents), or as a threat – 'for their views may challenge the social order' (Mayall, 1996:200). This is particularly the case with allegations of child sexual abuse where children are deemed to be unreliable witnesses (Essex, 1997), suggesting the status of children, and their views, occupy an uneasy position within the rights discourse.

As stated in chapter 2, I was unable to interview children directly either because of their age, the severity of their communication and cognitive impairments, and because those children who were cognitively able to express their views used a range of communicative techniques. For example, Judy used sign language while Patrick, a communication aid. For these reasons I asked parents what they knew about their children's views on tube feeding. Data collection by proxy is problematic because of its mediated nature and the displacement of experience onto carers, however to some extent all accounts are mediated, either by the participants themselves, or by researchers representing the views of others. Notwithstanding these problems, it is worth exploring parental accounts of the issues for their children.

Judy first had a gastrostomy when she was aged six, which was removed six months later for both practical and aesthetical reasons:

She wasn't happy with the look of it really, obviously it was quite bulky, at the time her little brother was quite small and starting to crawl and he could perhaps, you know, if he was playing with her, pull it. [Judy's mother, 1/2]

At age eight, following a deterioration in her feeding and growth, the decision was made for Judy to have another gastrostomy. Judy's mother spoke of the difficulty of making the decision the second time because Judy was more able to communicate her opposition to the idea of a gastrostomy. Her opposition was attributed to her 'age', a greater awareness of her 'image' and the attitudes of her school peers. Her mother was therefore concerned about the psychological impact of the gastrostomy compared with the earlier experience when Judy was younger.

In order to demonstrate Judy's ambivalence toward her tube, her mother gave the example of the doll. The first time Judy had a gastrostomy she delighted in her doll also having one and feeding tubes would feature in all her drawings. However this time around Judy refused to allow her doll to have a gastrostomy. Her mother represented this as an indication of her daughter's opposition to the tube. Judy's ambivalence was also apparent in her desire to have the tube removed when she was older. The example illustrates the complexities involved in the partnerships with children discourse as it raises the issue of whether Judy would have the right to have the tube removed, possibly against her mother's wishes (Ross-Friedman, 1998).

Although Judy could see the benefit of the tube (e.g. no choking) she also found it embarrassing. However, at times she would forget about her embarrassment and undress in public and show people her tube. These attempts to engage people with her tube were not always successful as they asked her to 'put it away'. Other's sense of embarrassment confirm the tube as something to be concealed and not for public display.

Socially she finds the peg [type of gastrostomy] a nuisance. She's very aware of her image and, you know, what people think, and so she'll, generally she tucks it in her knickers but when she first had it put back in she wouldn't wear certain clothing, she didn't like it to be seen. Down the line, she's actually relaxed about that, and I think that's just a Judy thing anyway, she forgets things, so she's actually forgotten now that she doesn't like the look of it, and she'll even get changed in the swimming pool at the moment and have people looking at her which, you know, she shouldn't do, but she's going through a phase at the moment where she's saying, why not, you know and completely forgetting it's in, so she's obviously got used to it? Um, but when she thinks about it she doesn't like it, you know, she'll hide it, she says I can't wear that

swimming costume because it's all bare, you know, it's all bulky, and ..., you know, she's quite image-conscious. [Judy's mother, 2/2].

Contravening social convention (to keep her stigma hidden) is attributed to her forgetfulness and her becoming accustomed to it ('and completely forgetting it's in, so she's obviously got used to it. Um, but when she thinks about it she doesn't like it, you know, she'll hide it').

Judy's mother impressed that her daughter was a very 'vain' little girl, invoking a discourse which is gendered, contrary to popular constructions of disabled people, and children in particular as un-gendered. The process of gendering Judy serves to personalise her and counters the image of her as a very disabled child. Judy's refusal to wear certain clothes if they exposed the gastrostomy (i.e. certain devices are bulky and may protrude through clothing) constructs Judy as an autonomous individual exercising choice which again subverts the image of Judy as dependent and disabled. Being vain is constructed as a property of the individual, yet Heenan (1996:28) comments on the 'public nature of women's bodies, both demanding and eliciting a self-consciousness constructed around body-consciousness'.

Nettleton and Watson (1998:17) problematise the use of the term 'body-image' in health and social scientific discourse, which implies an individualised and static notion of how the body is experienced rather than recognising it is socially mediated. In fact, it is determined by context and social relations, which was apparent in Judy's ambivalence about her tube, sometimes hiding it and at others, forgetting all about it, suggesting our body image is not fixed but fragmentary and variable.

Strategies adopted to 'normalise' Judy's feeding, using the tube for overnight feeds for example, did not always succeed in keeping her feeding situation concealed from others; when she participated in activities, swimming and P.E. for example, the tube was visible. It was also difficult to conceal the tube if she had friends to stay overnight as they would see her 'hooked' to the pump. However, her dislike of the pump also related to the way the tube restricted her freedom and spontaneity of play, for example jumping out of bed. The equipment is restrictive and presumes a passive, docile child.

Care and control are confounded through the restraining effects of the technology. Care and responsibility are reconfigured as control and restraint predicated on surveillance:

- G: So we were just talking about her reaction with friends and feeding, has she said why she doesn't like to do it particularly?
- M: I think it's because she's restricted in her movement, she can't get up and down with them and run around and misbehave, has to stay in bed, I think that's the main reason. But I think she finds it a bit embarrassing, you know, as well, doesn't like to be different so that's the reason, and it doesn't go beyond that, she doesn't think about why, she just knows that it's not nice to be different to them. [Judy's mother, 2/2]

Similarly, the way different contexts mediate perceptions of the self and body was reflected in Paul's mother's rationalisation for why a gastrostomy was preferable to a nasogastric tube. She spoke of Paul's reluctance to have a nasogastric tube outside the hospital environment because of its visibility and the lack of a peer group that also had them. Conversely, she constructed the gastrostomy tube as more acceptable because other children at school had them. Whereas the nasogastric tube signalled difference, the gastrostomy was acceptable because it signalled something in common with the other children. The norms of the peer group and associated contexts - hospital, school and outside - are drawn upon to illustrate the appropriateness and acceptability of the different types of tube. Nasogastric tubes were seen as acceptable in a hospital environment, although this was later qualified with the statement: 'when he wasn't seeing anyone', suggesting the importance of context in mediating notions of stigma:

- M: and I think he's very aware, you don't see people going around the street with tubes coming out of their noses, which is why he didn't want it when he was not at the hospital. But in hospital where it was a hospital environment and he wasn't seeing anyone, he was shut in a room, he was happy to have it.
- G: So you're saying there's something worse about having a tube in the nose?
- M: I think so, I think it's a lot more visible
- G: Rather than a gastrostomy?
- M: Than a gastrostomy and also no one at school has a NG tube, whereas there are kids at school who have gastrostomies, he knows this little boy in his class who's got [name of illness], he's permanently fed by his, he has a pump at the back of his either chair or the standing frame he's in and he just has this permanent tube and Paul's always known that [name of child] has always been like that...So an element of that's a peer group, he can associate that, but he doesn't have a peer group who have NG tubes. [Paul's mother, 1/2]

Conclusion

In this chapter I have expanded on ideas around difference, shame and stigma in relation to feeding and feeding technologies and discussed a number of theories which draw on traditional formulations of stigma as discrediting. Disability rights activists have challenged the role of medicine in defining dominant constructions of disability as an individual impairment and a personal tragedy. They criticise theories of stigma which describe, rather than explain, people's beliefs because they reinforce 'the dubious proposition that people do, in general, fear differences' (Abberley, 1993:110). Goffman's theory of stigma is similarly criticised for framing the concept of stigma as a personal problem which locates disability within this ideology of tragedy and individualism, rather than a form of social oppression which serves to exclude disabled people (Oliver, 1993;1990). As Saraga (1998:87) states, a critical deconstruction of the term disability shows that the term reflects 'a site of political, medical, academic, legal and moral contestations'.

Similarly, theories of coping and adjustment, rooted in psychological models, are also seen to perpetuate disability as an individual pathology. In describing individual and personal responses to stigma, such accounts fail to theorise the reasons why people, or attributes, are stigmatised in the first place, nor do they consider the possibility of resistance in the form of a collective response (Oliver, 1990). The deaf community, for example, reject the idea of deafness as a disability but rather normalise this as a cultural form and define their needs in terms of an oppressed linguistic minority (Saraga, 1998). Issues of stigma, coping and adaptation are concepts imposed upon the deaf community who may not accept that these processes describe or reflect their experiences. Concepts of coping and adjustment, enacted and felt stigma should be reformulated as modes of oppression (Scambler, 2004).

Starr (1992:157) argues that categories (dis/abled) do not merely reflect natural differences among individuals, but are written into institutional structures which create, define and shape them. As such, all kinds of classification reflect the structure of society. Parker and Aggleton (2003:17-19) suggest stigma and stigmatisation function, 'at the point of intersection between culture, power and difference'. They argue that

‘stigmatisation and discrimination must be understood as social processes linked to the reproduction of inequality and exclusion’. Deviance then is the politicisation of stigma (Scambler, 2004).

I have described how parental accounts of tube feeding appear to suggest a normalising effect once the nasogastric tube was removed and replaced by a gastrostomy feeding tube. In Goffman’s terms this would allow children and their families to pass as normal as they move from the category of the discredited to the discreditable. However, given many children also had other stigma cues, such as wheel chairs or oxygen tanks which would serve to discredit them, the distinction between the discredited and the discreditable does not seem to allow for the fact that children could simultaneously be discredited and discreditable. This suggests a need to theorise stigma(s) in the context of multiple disabilities given children referred for a gastrostomy had a range of health problems, including epilepsy and cognitive, visual and hearing impairments.

The imperative to pass as normal is similarly questionable, and I gave the example of Nicki’s mother earlier in the chapter, suggesting Goffman’s (1990:25) notion of ‘covering’ in order to ‘pass’, may not always be desirable. Similarly, the labelling of a child with a disability, rather than stigmatising them, can provide a passport to scarce resources as families are forced to compete for health, social care and, educational provision. Passing as normal does not always confer resources (Crane et al., 2002).

Discourses of normalisation permeated women’s accounts of feeding, mothering and child development. As such children who are fed by tube were constituted as not normal, as other. Theories of stigma, however, fail to account for the reasons why particular aspects of infant feeding and nutrition come to be stigmatised in the first place. When women make decisions about infant feeding they do so in the context of what they think children should be like, the idealised child, and what they think they should be like as a parent, the idealised mother. Within this context electing to have a gastrostomy may render both mother and child deviant.

Gray (2002) suggests that courtesy stigma is not limited to social interaction, as implied by Goffman, but rather parents of disabled children are rendered discreditable – ‘as a

product of their larger biographical relationship with their child'. However, Gray fails to adequately theorise the gendered nature of this biographical relationship. As such the notion of courtesy stigma has different effects on men and women because of the dominant and regulatory discourses of mothering which hold women responsible for infant feeding and growth. Felt stigma in this example, is a form of governmentality (Scambler, 2004).

A mother who has a disabled child who is poorly nourished is subject to a number of regulatory practices which render her culpable and challenge her competency as a parent. A man struggling to feed his disabled child will attract sympathy, while a mother reproach. Stigma theories fail to theorise the role of dominant regulatory discourses in constituting subjectivities and women's responsibility for reproducing cultural identities (Yuval-Davis, 1997:43). In England, women's responsibility for the health of the family, and hence the nation, is enshrined in the government's attempts at improving health and nutrition (Department of Health, 1999). This not only regulates women's mothering but their sexuality and demarcates who is fit to parent with the emphasis on the prevention of teenage pregnancy. Stigma theories therefore fail to theorise regulatory practices and, subsequently, oppression.

The designation of children as disabled and malnourished forms the basis of the control and exercise of power for such classifications serve to normalise children by 'rooting out 'deviance'' (Atkin, 1991:40). However, as I have argued, the category of deviance extends to the mothers of children who are rendered culpable within dominant mothering and clinical discourses for: having a disabled child, failing to establish a feeding relationship and, where women resist, failing to accept clinical recommendations not to feed orally, or to feed more. This positions women in a classic double bind which is likely to have consequences for their mental well-being. In the next chapter I discuss the role of regulatory discourses in constructing the link between feeding and women's mental health. I explore discourses of coping and adjustment in relation to ideas about governmentality.

11. Women, mental health and feeding

'He hasn't got the maternal obsession about feeding' [Nicki's mother]

Introduction

In this chapter I am going to discuss discourses of mothering in relation to women's mental well-being. In order to foreground the discussion I draw on the context of a psychological tool, the Questionnaire on Resources and Stress-QRS (Friedrich et al., 1983), which was used as a measure of family stress and coping in the clinical evaluation (see appendix 5). The tool pre-supposes that mental health, resources and coping are attributes of the individual, which can be reflected in the form of a score and compared to norms. I suggest that psychology's focus on coping and adjustment further entrenches notions of difference in its production of categories of individuals (i.e. the adjusted, the maladjusted) and as such, represents a form of governmentality (Saraga, 1998; Oliver, 1990). I argue that psychological tools, far from being scientific and objective, reflect the core cultural values of the rational, self-contained individual and arose as a result of a particular historical condition (Sampson, 1977). I argue that women's subjectivities, constructed by dominant discourses of mothering and reproduction, have implications for their mental health. I then discuss the rhetoric of blame and the personalisation of risk in relation to decisions about infant feeding.

It's all in your head: learning to cope

In the previous chapter I discussed how stigma, coping and adjustment reproduce difference and otherness and serve as a form of oppression, such that, it is incumbent upon people experiencing illness or disability to cope. Rose (1990:105) suggests 'government depends upon knowledge' articulated through vocabularies which 'describe the object of government and the invention of devices to inscribe it'. The 'psy' disciplines have constituted subjectivity and intersubjectivity 'as objects for rational management' producing the languages of government through which 'mental

hygiene, adjustment and maladjustment' are spoken about and normality produced (Rose, 1990:106). Science is implicated in the regulatory systems which 'codify, calculate, supervise, and maximise the levels of functioning of individuals' (Rose, 1990:109 drawing on Foucault, 1977). As discussed, the associations between 'governmental ambitions', science, professional expertise and individual aspirations are fundamental to the way liberal democracies are politically organised, that is, through persuasion rather than coercion (Rose, 1990:107).

Modernity was characterised by the move from a religious to a secular order and science played an instrumental role in the production and evaluation of individual experience (Bondi and Burman, 2001:7). Sampson (1990:119) suggests the process of individualisation in the seventeenth and eighteenth centuries created a 'free-standing, detached individual' and the need for a 'regime of societal control' based on scientific knowledge that would 'manage this new social character'. This period also saw the rise of the rational bourgeois, and culturally masculine individual. Along with the notion of the individual came the notion of the 'individual psyche as a site of self-reflection and regulation', and measurement (Bondi and Burman, 2001:7).

Rather than describing personhood, the 'psy' disciplines have played a fundamental role in the production of the individual, such that we learn there are people with 'Type A' personalities, and that individuals have an 'internal' or 'external locus of control', attributes measured through psychological tools and assessments. These tools are promoted as objective and scientific measures of psychological functioning, and yet they are premised on a particular construction of the individual; that of the agentic self-contained ('culturally masculine') individual typical of western liberal democracies, and represents a cultural ideal (Sampson, 1977; Flax, 1990). Moreover, these constructions have ideological effects. As Stainton-Rogers et al., (1996:121) suggest, 'within the prevailing individualism of dominant US culture, 'internality' is seen as much more desirable than a belief in chance'. Bondi and Burman (2001) argue that mental health is inextricably linked to a philosophy of liberal individualism. Moreover, they suggest that these constructions privilege the values of autonomy and independence 'at the expense of women's relational and situational identifications' (2001:20).

Parents of disabled children are generally constructed as experiencing stress, depression and loss within what has been termed the stress reaction or loss paradigm (Avdi et al., 2000; Magill-Evans et al., 2001) despite research that suggests mothers perceived their children to be a source of happiness and personal growth and maturity (Hastings, 2002). Mothers are commonly characterised as over-protective, anxious, or as having failed to adjust to the disability, or accept the diagnosis. Family dysfunction is assumed to be related to the child's disability. Definitions of what constitute effective coping tend to be somewhat subjective but generally incorporate notions of self-efficacy and problem solving (Beresford, 1994). These constructs are represented as coping styles and script out factors such as socio-economic status and education, which may also affect people's ability to cope.

In chapter 7, I discussed how women's accounts of feeding drew on the construction of the idealised child developing towards adulthood and self-sufficiency and how infant feeding practices were informed by this particular construction of the individual. The QRS, discussed at the beginning of this chapter, also reflects this construction of the child, and family coping and adaptation.

The QRS is designed to measure the impact of a sick or disabled child on other family members. It is considered to be a general measure of 'adaptation' and 'coping' and looks at both the positive and negative impact of disability on the family. The 'parent and family problems' scale measures respondents' perception of problems in the family, including poor health, the demands of care and 'limits' on family opportunity. The 'pessimism scale' is characterised by negative attitudes towards the child achieving 'self-sufficiency' including, the 'prohibitions' of overprotection and dependency. Although, there has been a move towards looking at the demands of care, rather than coping styles per se, in relation to caring for a disabled child, rarely is attention paid to the material factors that structure women and children's experiences (Cohen, 1999). For example, one of the statements in the QRS asks whether the family 'has to do without things' (see item 1, appendix 5), which is presumably attributed to the child's disability despite evidence to suggest that families incur substantial costs in caring for

disabled children (Dobson et al, 2001)²⁶. Moreover, a survey by MENCAP (2001) reported that 78% of families received either no support, or less than two hours per week, with caring at home. Similarly, only 41% of families in the interview study had access to respite care which ranged from four hours per week, to access to a shared carer once a fortnight for a few hours, to 28 days per year.

Caring is made easier when carer support and resources to carry out adaptations to the home are available. A loss of income, because parents have had to give up work to care for the child can also affect mental health. In the interview study there was evidence of a strong gendered division of labour with respect to feeding and child care generally. This was usually because a decision had been made for the mother to stay at home while the male partner became the primary earner. Further, there was evidence of male partners having to radically change their working patterns: the loss of shift work, changing to shift work, or becoming self employed, were strategies adopted in order to have more flexibility to help with caring. Getting time off work for the children's hospital appointments and periods of illness was often difficult and depended on the good-will of employers, or favours from work colleagues to be re-paid at a later date. Those who were self-employed lost income through time off work. For these reasons, it was the mothers who generally attended the hospital appointments and subsequently took the responsibility for liaising with health professionals, obtaining information about operative procedures, relating this information to partners and, ultimately, making the decision to proceed with surgery.

The differences in women's material circumstances were most evident when visiting families in their homes. In one example, the family (white, middle class) lived in a large and luxurious house in a desirable part of London. There was a live-in carer who was paid for from personal resources. Adaptations to the property were being carried out to facilitate wheel-chair access. There was plenty of space where we could carry out our interview in private while the carer looked after the children in another part of the house.

²⁶ It costs on average £7,355 per year to raise a child with significant impairments compared with an average of £2,100 per year for a non-disabled child (Dobson et al., 2001)

In stark contrast to this family, another mother I interviewed (an African refugee) was living in Bed and Breakfast accommodation. She was living in one small room with two children and her own mother. There were only two beds for the four of them. When I arrived the grandmother was hand washing bed linen in the bathroom annexed to the room. They shared a kitchen with a number of other families. Access to their room was by means of a fire escape as the main entrance to the hotel was kept locked. The mother did not have a car, nor did the child have a wheelchair. Further, the proprietor restricted visitors to the residence and I had to pretend I was a health professional in order to gain entry. The family did receive some help with care provided by a charity which was hugely appreciated, not only practically, but in terms of emotional support and friendship. The day I visited was quite warm and the windows were open. The noise of the traffic made interviewing difficult and progress was further inhibited by the arrival of one of the child's therapists. There was nowhere else we could go to carry out the interview. It was clear that appropriate housing, and access to a washing machine and a car would have made a big difference to this family (who fortunately were rehoused).

Further, the individualisation of mental distress fails to acknowledge that discourses of mental health are gendered, raced and classed. Women are consistently reported to have a greater prevalence of depressive disorders than men (The Mental Health Foundation, 2003), and women from 'minoritized' groups are more likely to be represented in the mental health statistics compared with British born white women (Bondi and Burman, 2001:9).

Who's to blame?: The social context of mothering and mental health

Riley (1984:52) notes that advice on children's management began as early as 1881. Advice on how to parent took on new depths in post-war Britain as child-rearing habits were seen as the key to understanding 'healthy adulthood'. This gave rise to a host of psychoanalytic approaches to child-development. Object relational accounts of the self stem from early relationships with primary caretakers, usually the mother. Problems are seen to be rooted in these early infant experiences of maternal failure (Elliott, 1994)

and presuppose that a woman's own mental health is dependent on having been adequately parented by her own mother.

British psychoanalysis has been criticised for positioning women as an object of children's developmental needs without acknowledging relations with other significant caregivers (Hollway, 2001); for example, the fathers' role and contribution appears to be absent from accounts of development. The privileging of the mother-child dyad fails to theorise other factors which structure the 'dyad', such as class, gender and race, and the fact that a woman's socio-economic circumstances may limit her ability to give emotional support to a child, or access networks of support (Flax, 1981). There are considerable social, emotional and economic costs involved in child care in general, and in caring for a disabled child in particular. Little attention has been paid to the fact that in meeting a child's needs, this may be at the expense of a woman fulfilling hers.

Ussher (1989) suggests women's identities are constructed in relation to their reproductive functions, such that pregnancy, childbirth and mothering frame women's experiences, whether or not they become mothers themselves, because of social pressures to reproduce. It is perhaps unsurprising then to find scientific discourses perpetuating links between women's reproductive capacities and their mental health. The majority of psychological research relating to women constructs their experiences negatively; post natal depression (and now, pre-natal depression), pre-menstrual tension, the menopause ('empty nest syndrome') - all of which portray women as dysfunctional and at the mercy of their biology. Ussher (1989:50) documents a number of psychological theories of pre-menstrual syndrome, which provide explanations ranging from rejection of femininity, anxious personality, emotional instability and psychiatric disturbance.

Feminists have argued that, far from being the pinnacle of achievement, the idealisation of motherhood denies the negative aspects of mothering and is oppressive to women whose experiences differ from those suggested by dominant ideologies. Anxieties about mothering and the associated responsibilities are rarely voiced as women are expected to get on with the business of caring. Within this framework, the depression some women experience after giving birth is perhaps understandable. Further, objectifying

depression in terms of medical explanations precludes a discussion of the socio-political context of mothering and obscures the wider issue of structural power relations in contributing to women's oppression.

There is an established body of literature that attests to the relationship between women's mental health and the structural position of women (Flax, 1981). Scambler (1998:110), drawing on the work of Chesler (1972), and Penfold and Walker (1984), suggests that as women's psyches have been constructed as inferior to men's, women are seen to lack the attributes necessary to equip them for a life in the public domain, leaving them to occupy a marginal role in the domestic sphere. This message is constantly reinforced by statistics on women's pay. For example, the Women and Equality Unit at the Department of Trade and Industry recently reported that women still only earn half as much as men and that half of women, compared with a quarter of men, have a disposable income of less than £100 per week (*The Guardian*, 13 July 2002).

Mental health and feeding

In the interview study women reproduced the associations between mental health and feeding in their accounts. If, as Briggs (2000:60) states, 'establishing a feeding relationship is a momentous experience for both mother and infant', what are the experiences of women who are not able to establish a feeding relationship?

Nicki's mother

I felt a strong identification with Nicki's mother. She was a very articulate and insightful woman with experience of working in the health and social services field. She held strong views about service delivery and issues around doctor patient communication, including how to break the 'bad news' to parents about a child's diagnosis. She was interested in professional training as a result of her experiences as a mother of a disabled child and frequent user of health and respite care. She expressed an interest in doing some research herself. She also lived in the same neighbourhood as

me and shopped locally. I initially met her in the outpatient clinic with her partner and asked if they would be willing to take part in the clinical evaluation. Her partner refused to take part in the research, stating that as the medical profession had not been particularly helpful to them, they were under no obligation to participate. At that time they were undecided about surgery. Nicki had a rare diagnosis unfamiliar to many doctors. In fact during the consultation the consultant had 'thrown' a medical encyclopaedia to a visiting doctor to check the diagnosis. The consultant's attempts to privilege the parents' expertise by asking them what the diagnosis involved seemed to estrange the father further. The mother agreed to take part in an interview.

In the following extract, Nicki's mother indicated that there had been a problem with feeding from the day Nicki was born. Her statement that there was a problem with feeding, but that she 'didn't know' because she had 'never been a mum before', is indicative of the lack of preparation many women feel when they have their first child. This initial period was experienced as stressful as the child vomited after every feed and failed to gain any weight.

Well there was a problem with feeding from day one, from the moment she came out from my tummy, (laughs) there was a problem with feeding, which was, but I didn't know because I'd never been a mum before and all I knew was that by the time it came to her six week check I was just dead on the floor. I was breast feeding literally hourly, or hour and a half, through day and night and I was just dead, and I think that's why the health visitor took one look at me and thought this can't be right. She was vomiting basically, virtually everything I put down, and she wasn't growing, she just didn't grow, she just didn't gain. It's like when she was born she was 5lbs 4 and it was like oh she'll be fine in a couple of weeks, she'll just gain and she just wasn't gaining. [Nicki's mother, 1/2]

As she recounted those early experiences she stopped to ask whether I had children, presumably to see whether I had experience of feeding a baby. She described this time as 'worse than' the period when they were waiting to receive an official diagnosis- 'I just didn't know what was going on':

M: Every single week I took her to the clinic she'd just like gained half an ounce and it was the most stressful time I can, have you got children?

G: I haven't got children no.

M: Well this is my first and I wouldn't have even known how stressful feeding is full stop, with a baby, but feeding a baby who doesn't grow is like every anathema of life really. It's just, it doesn't go your way and you can't really work it out. So yeah that started from day one, and then it was well the milk's not good enough and so I was trotting along to [health food shop] and getting good organic stuff to eat and loads of liver. And then they decided my milk need to be pumped and added calories to, so I did all that, pumping on one side and feeding on the other, and so I was just in fact it's worse than, it seems like it was worse than the long diagnosis period all that because I just didn't know what was going on and she just wasn't growing, dreadful, really bad. [Nicki's mother, 1/2]

In the survey conducted by Newson and Newson (1971), they found women gave 'highly stereotyped' reasons for not breastfeeding, such as deficiencies in their milk. Similarly, with Nicki's mother it was assumed that the reason for the child not growing was because her milk was 'not good enough'. Initially Nicki's mother assumed responsibility for her child's poor growth with attempts at improving her milk by supplementing her diet with 'good organic stuff', drawing on a 'natural equals better' discourse. Later in her dealings with health professionals she exonerated herself from the responsibility of Nicki's poor growth with the discursive shift: 'Look this child's got a problem'. However she assumes responsibility for effecting a better outcome for Nicki with the words -'I'm still in the mindset that I think I can'. This contrasts with her partner's approach to feeding, with the comment that the child has a condition over which they have little control:

So if she's had a bad day I also worry like mad and I count up her mils and I think she hasn't had enough, so I'm trying to think shove a bit in, shove a bit in. It drives [husband] crazy my moods on this, because he just says 'Look, this child's got a condition, we can't affect this.' But I'm still in the mind set that I think I can. [Nicki's mother, 1/2]

Feeding difficulties are rarely alluded to in child-rearing manuals. Further the idealised image of motherhood, often perpetuated by baby books, and the lack of information about disability, mean that when women's experiences do not accord with those described, this leaves women feeling they are somehow responsible and that they have failed. The link alluded to between feeding and attachment can make women feel inadequate if a child fails to feed. Drs Spock and Rothenberg (1992:365) suggest:

'[Parents] are apt to feel guilty, imagining that their relatives, their in-laws, the neighbours, the doctor, consider them neglectful parents'.

Again the link between mothering and the responsibility for feeding is apparent in the way mothers mentally calculated the quantity of food children ate, usually in terms of specific items. Calculating quantities in terms of millilitres or ounces is an extension of this monitoring, though obviously unusual. Whereas Nicki's mother calibrates food in terms of ounces or millilitres, reflecting Nicki's age and the fact her food intake is primarily in the form of purees and liquids, Shaun's mother quantifies his intake in terms of calories and size of portions. Consulting a food diary she is able to describe good and bad feeding days. The level of detail is quite striking. She acknowledged that some days Shaun probably only ate to please her:

I've just opened the book at random, and er on the 27 January you had one packet of Cartoons, which are a miniature packet of biscuits, probably er sort of no bigger than the top of yer thumb and water, that was all day. So I mean that's that's what I call a bad day, but there're days when Shaun really just doesn't want to eat and he just does his best to please me probably... felt quite sick, he did eat a few jelly sweets, what we call the penny sweets, um end of January we were going through a bad patch (laughs). But as I say going back to last week when things have picked up... (pause) these last few days, been eating two toasted sandwiches, um, I looked it up and it's nearly 100 calories per slice, each slice was 94 but I only cut the crust off, but you had the low-fat spread so it was then 100 calories per slice, so that was 400 calories. And on a particular day some ice-cream as well, and it was, that's a good day. [Shaun's mother, 1/2]

Nicki constructed feeding as an activity that dominated her life: 'there are days which are just ruled by feeding'. When her partner took the responsibility for feeding, she described herself as unable to 'switch off' as she mentally calibrates Nicki's food intake. She constructed a link between feeding and mental health with the phrase: 'oh it's just mental stuff and nerve making obsessive really':

And I'm very tuned in, like he was feeding her last night and then he was really slow in getting the food warm and I could tell she was hungry because she was hiccuping and so I ended up warming up the food and so I mean I can't switch off, that's my problem, I just can't. Unless I'm out of the room or away I can't switch off, and then he doesn't sort of check how much she's had the last feed, whereas I'm always going she had three so she's alright to have one ounce, or she's had two ounces so she needs another two, oh it's just mental stuff and

nerve making obsessive really. Yeah so he's feeding her for an hour and it takes ages he just goes mad, he says 'It's just taken me an hour.' And I think yeah that's what I do all day, that's what I do. [Nicki's mother, 1/2]

Post surgery Nicki's mother continued to invest a lot of time orally feeding Nicki. She described feeding as stressful because of trying to juggle between tube and oral feeding. The decision to have the tube was described in very positive terms- 'absolute right thing to do', the 'best thing' and she expressed a 'huge relief' at knowing Nicki was obtaining an adequate nutritional intake when she fed by tube:

It's all, it's all, basically, I'm thrilled I had it done and I just think it was the absolute right thing to do when I did it, the best thing, huge relief that I know now that she's getting 8 oz at night, and some days, she was getting less than that in the whole 24 hours. It's still, I still find it, I just think, you know, I still find the whole feeding thing very stressful, because I am trying to juggle now, she's going down a slippery slope now of not wanting anything by mouth, and I still spend an awful lot of my day time trying to feed her orally. [Nicki's mother, 2/2]

Nicki's loss of interest in feeding by mouth is constructed negatively - 'she's going down a slippery slope' which resonates with Cathy's mother's use of the metaphor of the ladder in chapter 6 to describe a deterioration in feeding. However, Nicki's mother also acknowledged that Nicki appeared to enjoy tube feeding - she smiles and claps and plays with the equipment. Again the play aspect of feeding is emphasised which resonates with other women's accounts.

The words 'if I could just give in' construct the task of oral feeding as something that dominates and must be conquered. She constructs tube feeding in terms of a forced choice - 'just give her the bloody food in the bag in the night and the rest in the tube in the day'. However for Nicki's mother there is no choice, signalled by the phrase 'but that's my thing'. Her sense of ambivalence is reflected in the idea that 'giving in', may leave her feeling 'happier', but is also constructed as a failing, for giving in is tantamount to surrendering:

And as I say, any disadvantages now I think are in my head, around my struggle with her feeding, I don't think that's anything to do with, you know, if I, you know if I could just give in I would probably be a lot happier. Just give her the

bloody food in the bag in the night and the rest in the tube in the day, but that's my thing, you know [Nicki's mother, 2/2]

The mother's account of her struggle around feeding resonates with Enlightenment rationalism (which viewed development in terms of liberation from nature)²⁷. For giving in is accepting the rational (the child has a condition which affects growth) over the irrational (the mother can influence growth); reason (tube feeding is the solution) over emotion (the desire to feed orally), and ultimately, masculinity (culture) over femininity (nature). There is also a Freudian metaphor in the account - the surrender of the pleasure principle.

When she reflected on what feeding used to be like preoperatively, she described it as torture-'it was just full-on, every day. It was sort of torture looking back'. Again this description echoes other mothers' accounts of feeding as 'battles' or 'wars' and contrasts with those descriptions of feeding as a 'special time'. The question is what is it that women feel they are giving up when they give in to tube feeding?

Child care manuals tend to construct weaning as a period of mourning or loss. For example, *The Encyclopedia of Pregnancy and Birth* (Balaskas and Gordan, 1992:205) advises: 'weaning a baby may not be easy and even if you are firm in your decision to do so, you and your child may be a little depressed for a while'. The view that weaning has a traumatic effect on children is attributed to Freud (Newson and Newson, 1971:54). However, in the Newson's study women reported very little difficulty with weaning.

Conflating weaning with feelings of loss denies the relief many women express at not having to breastfeed which they may find restrictive, uncomfortable, embarrassing and difficult to accommodate if employed, or outside the home (Birkett, 2002). Balaskas and Gordon (1992:205) advise that breastfeeding for anything between one and four years is 'natural' and that children are 'likely to be very healthy, independent, confident, and secure with a strong emotional and psychological foundation for the

²⁷ This idea comes from (Elliott, 1994:12) in his overview of Freud. Freud's thinking is often characterised as having an affinity with Enlightenment rationalism because of a fundamental opposition between the pleasure and reality principle.

future'. Again, a link is constructed between feeding and children's psychological development.

Not only is there little evidence to support the authors' claims, but given that many women may have to return to work for economic reasons, and that over a four year period they may expect to have more children, the advice seems somewhat impractical, and is informed by the dyadic model of parenting. Further, reactions to feeding four-year old children in public when there appears to be little tolerance of feeding small babies, can only be surmised. For some women in the study, giving up oral feeding was constructed as a loss, informed by the weaning-loss discourse. However, as I have argued throughout this thesis, investments in oral feeding are overdetermined by discourses of gender, the family, child development and cultural prescriptions that serve to normalise feeding.

- M: [name of husband] is about 1000% more relaxed than me about it all. He's completely Mr Chilled, just does not get stressed at all about it. It's weird, isn't it?
- G: Why do you think that is, what makes the difference?
- M: Umm, I think he's always had this thing that she'll only eat what she can eat, we can't change that, that's her condition, um he's just more accepting, he hasn't got the maternal obsession about feeding. All my friends have got it as well, I mean I've got it really badly but every mother I've met is the same, it's like biological almost [Nicki's mother, 1/2]

In the above extract, an important aspect of the mother's talk is that she is justifying her feeding decisions by drawing on a biological discourse to account for her actions. The biological discourse is normalising and gendered – 'all women have the maternal obsession about feeding'. However, she distinguishes between the position of other women – 'all my friends have got it as well' – and herself, with the position call: 'I've got it really badly', and therefore demarcates herself as 'outside' of dominant mothering discourses. The cool, accepting, rational (masculine) approach to the child's condition exemplified by her partner ('we can't change that, that's her condition'), contrasts with her description of herself as 'maternally obsessed', constructs different positions for men and women within discourses of care. The discourse of 'maternal preoccupation' resonates with Winnicott's (1965:15) assertion that women's 'primary

maternal preoccupation' with their baby, which although like an 'illness', is 'normal' and 'healthy'. It is only when the mother fails to return to 'a normal attitude to life' that she is described as having a 'pathological preoccupation' (1965:16). The difference between a healthy and unhealthy preoccupation with feeding disabled children would appear to be a fine one.

The discourse is also classed as women from less privileged backgrounds whose material circumstances do not allow them to spend prolonged periods of time feeding - whether because of work demands, the demands of other children, or simply through exhaustion - may be singled out for criticism for their lack of sensitivity. For women who are not prepared to invest this time and energy in feeding will be seen as lacking, sometimes by other women, or professionals. A mother may feel rejected by a child that refuses to feed and this rejection may be seconded by professionals with their advice to 'persevere', which may inadvertently imply that women are not trying hard enough. Professionals may underestimate parental anxiety:

So the bad days are, yeah puking or not eating or will take an ounce and then nothing and then suddenly she'll want three ounces, you know totally all over the place and I feel I can't go out, or if I go out I'm rushing to get home so I can feed her, or take a bottle and she won't feed when she's out because she's distracted or there are days when they are just ruled by feeding. It's the majority actually if I'm honest, and I get good days like yesterday which make me in such a good mood. And my moods are totally related to her feeding, you know if I'm depressed it's usually about feeding. [Nicki's mother, 1/2]

In her account Nicki's mother constructed a link between her mental state and feeding such that a 'bad feeding day' left her depressed. If the day is ruled by feeding a child that refuses to eat (and grow); and in the absence of alternative outlets where women can feel a sense of achievement or validation it is perhaps not surprising that women feel they have failed. Walkerdine and Lucey (1989:29) suggest disciplinary practices leave women feeling they have to meet needs. When women are unable to meet these needs they are made to feel guilty and inadequate.

Women with children with feeding difficulties may experience increasing social isolation, either because of the demands of care, the reactions of relatives and friends who may avoid the ill child, embarrassment about feeding a child in public or a lack of

material resources. Families in rural locations may be particularly vulnerable because of a lack of transport and services for disabled children generally. Mothers who are spending the whole day feeding because there is no one else who can take over may have little opportunity for social outlets. Given children often refuse to be fed by anyone else except the mother, this can forge an even greater dependence.

The withdrawal of professional help was given as a reason for increasing social isolation for Duncan's mother, suggesting a complex interplay of material, personal and social factors:

- F: The biggest help for [Duncan's mum] was having the nurse here twice a week, but they've taken that away because she's working at a different place now and she can only come once a week. But whereas before she could perhaps go out shopping or something like that, now it's just necessities.
- M: You nip out and get what you need.
- F: There's no time to say oh well I might pop into my friends for a coffee or anything like that because you've got to get back to do Duncan, and if you take, she tends to miss out on a lot of that because the rigmarole of taking everything with her.
- M: And then you're always worried in case he's going to chuck up in the house and things like that, which they don't mind but it's like embarrassing if you've covered something of theirs, it's like no I'll go home and do the feed.
[Duncan's mother, 1/1]

Prior to surgery, Zarra's mother indicated that 90% of her worries related to feeding. She constructed the gastrostomy as something that would relieve the stress of feeding (knowing Zarra was obtaining an adequate intake of food) but indicated that her worries about feeding would continue, given her desire to feed Zarra orally. This again suggests that women's investments in oral feeding involves more than nutritional considerations:

- G: And what about for you though, how do you think the gastrostomy might help you?
- M: Oh how it might help me, just because I would stick her on the same way I'm doing now, I mean just, it's like 90% of my mind, of my er, worries, are towards Zarra's feeding, so it will be, I think it will be still the same, I mean like in terms of getting her new stuff, trying new things, trying all the time, giving her whatever she wants all the time, is just the difference between milk is, if she doesn't eat like she does in some days, I wouldn't be thinking oh my God, she didn't have anything today and she didn't have anything yesterday, what will

happen tomorrow, and I just think the stress will be less, and if she's having milk and especially I mean the amount she will be having, it'll be much, much greater than any amount she had at any day during her life. [Zarra's mother, 1/2]

In the interview following surgery she affirms her determination to persist with oral feeding:

G: Have you thought about maybe giving up on the feeding by mouth, and doing it all with the gastrostomy?

M: Oh no, no way, no, no. I mean, the gastrostomy, I choose it or we choose it only to support her, I mean not really to give up on the food by mouth, never, no. [Zarra's mother, 2/2]

In some cases, difficult feeding was exacerbated by expert prescriptions. Garry's mother spoke of the difficulty of following a feeding regime that took eight hours of the day. Despite the fact she was receiving advice about oral feeding from an alternative therapy centre that espoused a philosophy of non-surgical intervention (and possibly, normalisation), the mother experienced some difficulties following the programme:

Um, there's only so much time in the day that you can sit and do other things, I mean if I'm doing his physio or if I'm doing other things for him and I've got other things I've got to do for myself, then because with the [name of alternative centre] way of um, teaching, or what they said to me, he should have meals six times a day. Those six meals a day took eight hours out of the day, so by the end of the day I was tired, and I'd done nothing else but try to feed him, you give him bits of gaps between those times and you give him little bits just to keep him going, and it's like, it was impossible. And I went back to them and I said, I can't do this because it's just taking too much time. [Garry's mother, 1/2]

In taking responsibility for Garry's physiotherapy, his mother assumes another (unpaid) role that would ordinarily be performed by professionals. These different roles confound care with control and surveillance. Every time a mother consults medical or complementary health specialists, their advice will usually entail some task, for example recording eating behaviour, keeping food diaries, and increasingly, taking part in research studies, all of which women must incorporate into their everyday routines, leaving very little free time.

Another mother spoke of how, following the insertion of a gastrostomy, she had been advised to tube feed every two hours, advice that she eventually disregarded as neither

mother nor child could cope with the feeding regime. It is not surprising that women describe themselves as 'obsessed' with feeding if advised to adhere to such regimes. In this case the mother resisted professional recommendations which serve to further regulate feeding and mothering through time management (Dayle and McIntyre, 2003).

So far I have discussed how my analysis of women's accounts constructed a link between feeding and mental health. The extent to which a gastrostomy relieves women from the task of oral feeding depends on whether they try and maintain oral feeding post surgery. I now explore in more detail how women account for their investment in oral feeding.

Difficult decisions: guilt, blame and regret

In chapter 6 I highlighted the way women constructed guilt in relation to the ease and convenience of gastrostomy feeding compared with oral feeding. I would now like to explore the issue of guilt, blame and regret in relation to decisions about infant nutrition.

If as psychodynamic theory postulates, feeding difficulties arise when there is a problem in the 'container-contained relationship' (Briggs, 2000), implicating women directly by their failure to respond sensitively to their children's needs, then perhaps we can see why many women experience guilt at not having established a satisfactory feeding relationship. These theories tend to position mothers as the focal point of the problem. For example, Briggs discusses Daws (1993) categorisation of archetypal mothers: those who underfeed their children and those who feed little and often. Fear of separation underlies the mother who snack-feeds her child. This pattern of feeding reflects her own hunger and need (at not being adequately mothered herself). Frequent feeding becomes a metaphor for the loss as a consequence of the unsatisfactory separation with her own mother. Food becomes a substitute for love and closeness. Alternatively, the withholding of food also reflects a form of maternal deprivation – 'a legacy of deprived and disturbing experiences' (Briggs, 2000:68). The link between children's earlier feeding experiences and later adulthood is made by Dr's Spock and

Rothenberg (1992:366) in relation to the 'over-anxious' parent: 'the strong feelings of anxiety, guilt, and irritation are partly leftovers from the same feelings implanted in the parents in childhood'.

Whatever metaphors are used to represent the feeding relationship within psychodynamic discourses, women are seen to be at fault for being bad mothers - a case of 'love gone wrong' – childhood problems occurring because of the mother's inability to manage the 'emotional economy' (Rose, 1989:155). Moreover, when a mother fails to nurture, her mental health is called into question, as in the case of the vegan baby story (discussed in chapter 1) where the failure of a mother to provide her child with an adequate diet was attributed to her mental state. In the mother's defence (not the father's) the defending lawyer attributed her 'obsession' to 'previous health problems' and described her as 'having a low level mental disorder [which] had resulted in an "obsession" with eating only organic, raw, vegan food' (*The Guardian*, 15 September 2001). The example resonates with the Victorian treatment of women who did not conform: they were labelled as mad. The argument becomes very circular: women who fail to nurture are mad and women who nurture too much are over-protective and needy; in short their mental health is also questioned.

The castigation of women as unfit mothers resonates with the narrative of the monstrous mother (Alldred, 1996; Creed, 1993). The monster narrative reflects a fear of the power women have over men and children: 'Images of the monstrous mother have included the overprotective mother who refuses to relinquish the child and so smothers or subsumes them; the selfish and withholding mother; and the all powerful and sadistic mother who threatens to castrate or emasculate men' (Alldred, 1996:143).

To some extent professionals reproduced the narrative of the monstrous mother in the advice they offered parents, for example, advising a mother that it was unsafe to feed orally by drawing on the analogy of a child drowning to illustrate the risk of aspiration, pathologises a woman's parenting. As one mother commented: 'it was like they were telling me I was killing my child'. This advice may follow consultations with other professionals who may have challenged a mother's competency by suggesting her child is seriously malnourished, needing to be fed more. A woman's mothering may be

further challenged when professionals video record her while feeding her child. This is not to render professionals in anyway culpable for doing what is ostensibly their job; I merely wish to highlight how professional discourses reproduce the rhetoric of blame with consequences for women's mental health and their willingness to interact with the health services. I return to aspects of professional practice in the concluding chapter.

I now examine the discourse of blame further by highlighting other areas where women held themselves responsible for their children's health. That women blame themselves for their child's disability is apparent in the next account where Zarra's mother reported that her relatives blamed her for her daughter's small size because she was unwell during her pregnancy and unable to eat. Her experience of the pregnancy as 'hell', or akin to 'dying', does not accord with the idealised image of pregnancy and motherhood as a time of fulfilment and bliss, an image popularised in child care manuals and women's magazines (Marshall, 1991):

- M: my parents, you know my family now, now, specially that there is always, I mean, I could see, I can see in their eyes that they are putting the blame on me, that Zarra's not growing, that Zarra is small, because I wasn't eating when I was pregnant, and I couldn't help myself, I was dying when I was pregnant, I couldn't eat anything. I couldn't eat. And I know there is, it is in their mind that yes, Zarra is small because I wasn't eating. And er, they don't say it but I do feel it. And she's not growing now, she's not alright, well it was my fault at first. So I don't complain to other people.
- G: You weren't very well during your pregnancy?
- M: It was hell, it was hell.
- G: Sick a lot?
- M: um and weakness. It was hell. Yes. [Zarra's mother, 1/2]

In her account, Zarra's mother made a direct link with her own inability to feed and the child's poor growth (Zarra is small because I wasn't eating). Her ambivalence about whether her behaviour during the pregnancy contributed to Zarra's small size was reflected in the comments –'I couldn't help myself' and 'well it was my fault at first'. Similar attributions of responsibility have been reported in other studies. Cohen (1999) quotes Parker (1996) who found parents expressed profound guilt at their child's condition and often reviewed their pre-natal behaviour as if they had contributed to a child's suffering by 'passing a bad gene'.

Henwood and Pidgeon (1994:234) argue that the attribution of blame is more than a rhetorical accomplishment and 'takes place within wider discursive or signifying systems' that have ideological effects. Urwin (1985:177) also notes 'aberrant' development is attributed to the mother and is taken as a reflection of her competence. Individual responsibility for illness is particularly prevalent in the West, a belief perpetuated by Health Education initiatives and governments (Helman, 1984). Gregory (1991:124), in her analysis of books on pregnancy, notes a 'silence' with respect to the issue of disability. With few positive references to disability and a paucity of advice, she concludes that disability is seen as something that should, and can, be avoided, if the mother takes appropriate care.

That women both feel, and are held, ultimately responsible for the health of their child even before the birth, and conception, is apparent from professional advice to women not to smoke, drink, take drugs (legal or illegal), eat certain kinds of foods during pregnancy, or generally engage in any kind of activity which is deemed detrimental to the child. Maternal culpability is such that in the US, legal injunctions and, ultimately, prison sentences, can be served on (predominantly working class) women who deviate from medical prescriptions about what constitutes appropriate health behaviours for pregnant women (Pollitt, 1990).

Research has established a link between a woman's emotional state during pregnancy and behavioural problems in children (*The Guardian*, 1 June 2002). The study, which achieved high media attention, suggested that mothers who were anxious during pregnancy were two to three times more likely to have children with emotional difficulties. The anxiety is thought to affect the brain development of the foetus. Shuttleworth (1994:40) notes how contemporary maternity handbooks recycle views from the Victorian era, characterised by a similar preoccupation with personal control, 'both of the body and of social and economic position'. The idea that maternal anxiety is harmful to the foetus resonates with the advice given to Victorian women to 'preserve a ladylike calm' (1994:38).

Miles (1988), in her study, noted that women with depression or agoraphobia also expressed feelings of guilt and self blame in relation to their children's quality of life,

which they believed to be adversely affected by their own mental health. She concluded that guilt is a characteristic of women's lives in general and not only those with psychiatric problems. The rhetoric of personal responsibility was apparent in women's accounts in relation to decisions about children's feeding management:

But I think, not because it's just a gastrostomy, I think it's the fact that he's going under a general anaesthetic, regardless of whatever he's having, it still gives me the feeling that it's one of those things that he could go under and not come back out alive with, and that is my fear, basically. And what's happening, last night it dawned on me why I felt very upset, cos I was crying last night a great deal, and the reason why I was crying a great deal was because I requested that he has this, you see, and that is a fear that if it goes wrong, I'll feel, my God, what have I done, I've put him under this. And I realise that at the end of the day, you know, he would be getting it so I had to justify my thinking around that. [name of consultant] wouldn't have allowed him to go for it unless he felt it was deemed necessary. When he had the hip operation they said it was going to be a hip operation, I didn't have the anxiety, you know, weeks before you know, we were given a date and I didn't have that anxiety, that, alright, he's going for an operation, I felt sad but I didn't feel the guilt. Now I'm feeling this guilt because I feel that I'm doing this, and I feel like, oh why can't I just stop, get him to feed properly and if he fed properly then we wouldn't have to be going through any of this. [Garry's mother, 1/2]

Garry's mother constructed a link between the decision to proceed toward a surgical solution and the risk of losing her child (because of the anaesthetic risk) as a result of her failure to establish oral feeding. Although most parents would feel anxious at the prospect of their child having an operation, indeed many fathers expressed such concerns, gastrostomy surgery is demarcated as different here because of Garry's inability to feed compared to another operation on the child's hips: 'I felt sad but I didn't feel the guilt'.

Similarly, Nicki's mother articulated a link between feeding, mothering and the responsibility for making the decision to go ahead with surgery:

Maybe I'm just making a big fuss about it, I don't know really. Maybe it's just a simple thing to stick a tube in. It's just a really emotional issue I think. I don't think the doctors realise it's an emotional issue for a mother. [Nicki's mother, 1/2]

When women express their concerns about surgery, they are often seen as over-anxious. Constructing the decision to proceed with surgery in terms of intrapsychic conflicts fails to acknowledge the social context of decision making and the fact that the burden of responsibility and guilt falls on women. Women often discussed their fears about the risks of surgery in relation to previous events or experiences where things had gone wrong. A failure to look at decision making in its social context and attend to women's concerns, pathologises their experiences by labelling them as anxious and unable to cope. Moreover, devolving decision making to women by presenting it as their choice is not necessarily empowering if they feel they are ultimately depriving their child in some way. Not surprisingly, when women were asked how they could be supported in making the decision, they responded in ways that framed the decision as their individual responsibility: 'you can't get support for this decision, it's something you've got to battle with.'

Currie (1988:248) in her research with women and their reproductive choices observed how women framed their decisions as their own responsibility according to a personalised biography rather than as the result of social and economic processes. She suggests that conflict and guilt develop during, and as a consequence of, making choices that appear as 'impossible alternatives'. Guilt and blame therefore arise from the contradictory positionings women find themselves in within discourses of mothering. As such, structural antagonisms become represented as personal choices (Currie, 1988:248).

Generally, women spoke of the need for information reflecting a variety of concerns, not only about the procedure but how gastrostomy would fit into the context of everyday life for both child and family. For example, the affect on activities such as swimming, physiotherapy, going on holiday, the child's ability to lie on her stomach and issues around oral feeding. Information concerning the use, care and management of tube feeding and the need for this prior to surgery was also requested. Further, parents felt they would like the option of talking to other families, including those with both positive and negative experiences of gastrostomy feeding in order to gain a more balanced view (and construct themselves as rational, and culturally masculine, decision makers). The benefits were seen in terms of talking to someone who could empathise

(having gone through the experience themselves), learning coping strategies, as well as being able to communicate in non-technical language.

Regret

Women also blamed themselves when things went wrong post operatively. In chapter 5 I described how Ricki's mother regretted having made the decision for Ricki to have a gastrostomy, particularly as he had not gained weight:

And we blamed it on, I blamed it on myself that I took him for the operation and my husband blamed it on himself. We just, umm, I don't know if it's a mistake that we have to live with. I don't know whether I should call it a mistake (laughs). [Ricki's mother, 2/2]

The laughter following her statement about whether to call the decision a 'mistake' is illuminating and possibly alludes to the notion that good mothers never make mistakes. In calling her decision a mistake she is attributing blame to herself. In conveying the sense of self-blame she experiences, Ricki's mother uses a medical metaphor to describe the 'somatisation' of her guilt. The metaphor draws on notions of disability and handicap. The child's suffering has rendered her disabled ('I can't move', 'it's like I've broken my leg', 'I can't walk properly'):

It's more under pressure I think. It's, it's the operation has, umm, I mean, Ricki has had the operation but I feel as if I've had the operation myself and I just can't move the way I used to move. It's like I've broken my leg and now they've put it in plaster but when they took the plaster off it's not, the bones are not straight, straight, and I can't walk properly, it's just that my life is umm always, you know, I worry now. Even more of a worry than before. [Ricki's mother, 2/2]

Women also expressed a form of regret when they were able to witness the benefits of the operation. For example, if the child had gained weight, was happier and contented, looked healthier or, was more alert and, responsive. Their regret reflected an anxiety that the delay in making the decision had deprived the child of a benefit that could have been claimed sooner, hence the unavoidable character of guilt and regret.

Conclusion

In this chapter I have further illuminated the contradictory and conflicting aspects of feeding and caregiving (Rose, 1994). Women may continue to feed orally because they believe it to be in their child's best interests in terms of ensuring their developmental progress, and in cultivating independence – none of which may appear very rational, but on further scrutiny, and as detailed in previous chapters, is very consistent with dominant discourses of child development and mothering.

Women are faced with enormous responsibility for making decisions about a child's nutritional management but may feel almost powerless in the face of the uncertainty as to whether their child will benefit, and if so, at what cost. Women are blamed and blame themselves for not having established a feeding relationship, and for their child's poor growth. They blame themselves when a gastrostomy is recommended, as this signals that they have failed, and when the procedure doesn't live up to expectation, or when it delivers noticeable benefits, women again blame themselves for having acted or not acted sooner.

The personalisation of responsibility stems both from the construction of the agentic self-contained individual and the move from what Beck (1992) has termed an industrial to a risk society (discussed in the next chapter). Women negotiating risks in relation to decisions about infant feeding may find themselves in a no-win situation because of their multiple and contradictory positionings vis-à-vis the mothering role, which have significant implications for their mental well-being. To act or not to act, this is the question. Yet both options can position women as neglectful for not doing the right thing. The issue of how women and their families can be supported through the process of making decisions about children's nutritional management fits well with contemporary debates about the psychosocial aspects of health and, social capital. I now move on to the concluding chapter where I elaborate on these ideas.

12. What constitutes ‘appropriate’ care and research practice?

Introduction

I intend to organise my discussion in terms of a number of topics that I have raised throughout the thesis that have implications for children’s care and clinical and research praxis. In the first section I briefly summarise the main tenets of the thesis. Then, I discuss the complex relationship between the rights of children and adults, and examine how law and child welfare are infused with normative constructions of the child informed by developmental theory, and the consequences for child protection. I then discuss what constitutes ‘appropriate’ care, and ‘appropriate’ research practice. I consider what a feminist approach brings in relation to these topics and what the policy implications might be. I end with some reflections on feeding and make suggestions for how future work on feeding and disability might be fruitfully developed.

So far I have argued that a major discourse in feeding disabled children revolves around malnourishment and the safety of oral feeding, prompting the perception of a need for an intervention in the form of a feeding technology. Concerns about children’s physical and cognitive development and parental well being are manifest through concerns about nutrition and parental feeding practices. In Foucauldian terms this represents a new ‘mechanics of power’ that constructs malnourished children as a deviation from the norm of an adequately nourished population (Dayle and McIntyre 2003: 317). I have argued that infant feeding is a disciplinary practice which forms part of the administrative apparatus for providing techniques of regulation (Foucault, 1988;1982). Clinical interventions become ‘programs of power’ by trying to correct ‘nutritional deficits’ and ‘malnourishment’. As such: ‘This invokes a rationality in which individuals become distributed, categorised and manipulated around a given norm. Problems are produced and solutions imposed’ (Atkin, 1991:40). I have demonstrated that science is inextricably bound up with notions of normalisation, including norms of mothering, child development and behaviour. Norms which infiltrate the home and community, including the health services, nurseries, schools, child-welfare agencies

and the courts (Rose, 1989:154), serve to regulate women and their children. Ideas about parental competencies however are not only gendered, classed and raced, but leave the most economically marginalised likely to be branded as unfit to parent. Normative constructions of children can have detrimental effects on children themselves. Alderson (2000:56) for example, suggests: 'Norms set by professionals become the basis on which professionals prescribe and sometimes impose 'needs''.

Developmental theory, initially premised on discourses of child-centredness, refocused its emphasis from children's needs, which constructed children as powerless dependants (Woodhead, 1990:75), to one of rights, which represents children as autonomous and free. Developmental theory therefore is deeply enshrined within the discourse of the rights of children. However, it is contradictory in its effects and serves to silence rather than empower children, as in the case of child-sex allegations (discussed later), such that some groups of children (and their parents) are constituted as having fewer rights than others.

I have also linked ideas about idealised and stigmatised mothers (Hill-Collins, 1999) and children to issues of citizenship, rights and nation and suggested that women play an instrumental role in (re)producing children's identities in accordance with normative prescriptions about children and their behaviour. Rose (1989) describes the family as instrumental in carrying out certain social obligations to reproduce and rear children and produce and regulate their subjectivities according to normative practices which are reformulated as the personal aspirations of its members. This may account for the resistances to feeding technologies which neither accord with normative expectations about child development nor parental aspirations for their child, or indeed, themselves as 'good' parents.

This is not to detract from the fact that many children and their families do benefit from feeding technologies and I have indicated that acts of resistance may not necessarily be beneficial to parents, or their children, suggesting 'resistance can have reactionary as opposed to revolutionary effects (Walkerdine, 1990:3). This is most obvious in terms of the harm/neglect children may experience through a lack of medical care, and perhaps highlights the contested and ambiguous status of children and responsibilities

for their 'ownership' within familial and state discourses that are intensified by their gendered associations.

In the child's best interests: protection and harm

Throughout this thesis I have argued that the construction of children as having rights independent of the adults who are charged with their care is inherently problematic and brings into stark relief examples where the rights of children and their carers conflict. Developmental psychology is premised on an individualist model of development. This individualism is also enshrined in the discourse of the rights of the child, for it presupposes that children exist as isolated units. The concept of the individual as free and autonomous with needs and rights that exist outside of social structures is fundamental to liberalism but fails to acknowledge that women and children, and disabled children in particular, have less autonomy, and rights, than men (Cameron and Fraser, 1984). In the introductory chapter I stated that as far as I am aware child protection procedures have not been used in respect of feeding and disabled children reflecting the unease perhaps about framing disability and feeding in terms of harm. I would now like to explore some of the tensions in the discourses of needs, rights and protection.

In deciding what constitutes the child's best interests, professionals increasingly rely on science and expert knowledge and, ultimately, the courts to resolve what are ostensibly moral issues. Scambler (1987:173) quoting Friedson (1986) for example, suggests that medical expertise has come to be legitimised in terms of formal knowledge which is privileged over other knowledges and that science and technology have come to pre-empt political debate and decision making which are increasingly presented as 'technical' decisions. The clinical evaluation for example, framed gastrostomy-feeding interventions in terms of an evaluation of outcomes, obscuring a wider debate about how society cares and provides for an increasing number of children with special needs surviving into adulthood.

I have discussed the way children's needs, which are defined in relation to the core cultural values of Western society, are presented as inherent qualities of the child and articulated as normative scientific practices which have implications for how the law treats children. Feminist perspectives, for example, point to the way the law serves as a legitimising discourse informed by a scientific rationality which produces particular constructions of the child (Bridgeman and Monk, 2000:5). The Children's Act 1989, which embodies the image of the child as 'vulnerable and in need of protection', informed by a discourse of child-centredness, is one example where the centrality of the child informs child welfare policy (Bridgeman and Monk, 2000:5). The authors point to the way adult perceptions of children as non-adults, or future adults, inform the ethics of protectionism and children as investments in the future. The law, however, does not merely protect but plays a disciplinary role in perpetuating particular constructions of children, while silencing, and harming, others.

The notion of protection locates children within the private domestic realm of the family (Bridgeman, 2000). The construction of the family in the private domain however serves to mask its social and economic function and contrasts with the increasing surveillance and regulation of family life. The private/public distinction has its roots in liberal discourse with its emphasis on *laissez-faire*, 'personal autonomy' and 'private choice' (Rose, 1989:124).

In contrast to the image of the vulnerable child in need of protection, we are increasingly witnessing measures to protect the community from 'anti-social' children, with the criminal justice emphasis on 'containment and control'. Constructions of children as 'villains' (Franklin, 2002:38) suggests children who occupy spaces outside of conventional norms forfeit the right to protection, as in the case of child murderers and, perhaps, disabled children.

Normative constructions of children are reproduced in the United Nations Convention on the Rights of the Child, endorsed by most of the world's leading nations, and aim to uphold universal ethics about the treatment of children. The Convention embraces a number of rights grouped according to the headings of provision, protection and participation, and exerts a powerful globalizing influence (Woodhead, 1990:79;

Franklin, 2002). Euro-US models of development are exported globally which serve to propagate the notion of a universal global child. As such, parenting practices, and indeed childhood experiences, which do not concur with the idealised standards of child and family life are constructed as outside of such norms and in need of regulation.

Article 32 of the Convention, for example, is designed to prevent children from engaging in activities that would interfere with their education and protect them from economic exploitation (Woodhead, 1990:80). This penalises the poor as many families in resource-poor countries rely on their children's ability to participate in work for their survival (Boyden, 1990); and it has resulted in policy, it could be argued, that is ethnocentric, classed and detrimental in its effects, with the most economically marginalised unable to meet the standards set by the convention. Images of economically active children subvert the discourse of the passive, dependent child, as does the image of children caring for adults, suggesting children's relations with adults may be better described as one of interdependency (Bridgeman and Monk, 2000). The authors also note a parallel with children's caring role and the hidden nature of women's domestic labour.

The aim of international policy makers has been to set a global standard of care as a basic human right (Boyden, 1990:198). This standard embraces a right to welfare, adequate nutrition and medical care and, as such, the rights discourse implies a contractual obligation to guarantee such standards – 'since embodied in the concept of right is a direct claim upon someone else' (Boyden 1990:192 quoting Alston, 1987). However it is difficult to see how a starving child in Africa with AIDS could make such a claim, or who would be held responsible for redressing the infringement of the child's rights. For example, would the drug companies, or governments (both Western and African), be held responsible for failing to make food and medication freely available; and here lies another example of how international law, aimed at protecting the intellectual property (i.e. profits) of drug companies through patents, is clearly at odds with children's rights to medical care. These examples attest to the difficulties of applying universal standards of care legitimated by a discourse of rights which aim to protect but, ultimately, silence diversity and difference with ethical consequences and adverse material effects.

That groups of children have different rights is clear in the case of child sex abuse legislation where child witnesses are viewed as unreliable and discounted. Few prosecutions take place where a child witness is under the age of eight despite the fact that a third of allegations raised come from this age group (Essex, 1997). Alderson, 2000:57) attributes this to developmental theory based on questionable Piagetian studies, which constructs children as 'morally immature' and unable to appreciate the perspective of others. She suggests myths about children's lack of competencies serve to undermine 'adults' sense of obligation to respect children's views'. Here again lies an example of how the law can inadvertently harm children while protecting the perpetrators of abuse.

In the introductory chapter I discussed whether disabled children have fewer rights than their able bodied contemporaries in relation to neglect through 'malnourishment', suggesting children have different and unequal claims on the right to be protected. Whether 'malnourishment' should be equated with maltreatment is uncertain given the lack of consensus amongst professionals about the growth potential of disabled children, except in relation to normative standards. However, it is unlikely that the idea of allowing 'nature to take its course', which may underpin professional/parental inaction, would be tolerated in relation to a non-disabled child ²⁸. The absent voice in the gastrostomy debate is indeed that of the child. However, it is clear that where children are consulted and express views that differ from their parents or doctors, the discourse of protectionism prevails:

Children's autonomy and rationality can conflict with the need to protect them from making decisions that are not in their long term interests (Dixon-Woods et al., 1999:778).

Here children are constructed as not 'rational enough' to make decisions about their future. These examples illustrate a complex juxtapositioning of rights and responsibilities.

²⁸ Many parents in resource-poor countries do not have the option of a gastrostomy for their child because of the lack of free health care and the associated costs of feeding technologies.

There is a tension within the children's rights discourse, therefore, between whether children are in need of protection, or should be treated as autonomous individuals with the right to self-determination. In a climate of increasing economic uncertainty within the context of globalisation, Lee (2001:34) suggests that children's identities are increasingly constructed outside the traditional boundaries of the nation state. Given the uncertainties associated with the global economy, it is unclear what kind of future citizen is needed. As such, the global child 'is positioned in overlapping states of dependence and independence'.

This tension is replicated at the intersection of clinical and parental definitions of what constitutes the child's best interests in relation to tube feeding. Clinicians are given the task of protecting children from harm (which is constructed in terms of the safety of feeding and adequate nutrition), whereas parents are additionally charged with the task of ensuring children's participation in family, school and social life. In interviews with parents, their accounts embraced the importance of providing children with opportunities for learning, for experiencing pleasure and, developing skills towards self-reliance, all of which parents constructed initially through the medium of food and eating. I argue that parental opposition to gastrostomy feeding interventions relate, in part, to constructions of tube feeding as a form of parental negligence, contrary to professional constructions of gastrostomy feeding as a parental duty.

The difficulty of the rights discourse for feminists is particularly apparent when we consider the way both children's rights, and their father's, can militate against those of the mother. The recent ruling that it was in the child's best interests to have the controversial MMR vaccine, the cases, brought to court independently by two estranged fathers against the wishes of the mothers and one of the children, illustrates how the rights discourse can disadvantage women, and children (Meikle, 2003). Alldred, (1996) also discusses how the discourse of rights has been used to disempower and marginalise lesbian and lone parent mothers by virtue of politicians drawing on ideologies of the family which claim it is in the child's best interest to be raised in a 'normal family', thereby demarcating who is fit to parent by controlling who has access to fertility treatment.

There is a tension therefore between the 'parents know best' discourse (which is also gendered as the example of the court ruling in relation to MMR suggests) reflected in the move towards greater parental rights, and increasing state regulation of families through social workers, the courts and government family education initiatives (McGaw and Lewis, 2002).

The adversarial approach to common law has been criticised for creating conflicting relationships based on competing rights (e.g. Bridgeman and Monk, 2000) and for reflecting the male values of 'individual autonomy, competition, and aggressiveness' (Childs and Ellison, 2000:11). An alternative approach drawing on Gilligan's ethic of care has been suggested, which holds that the 'law should accommodate both justice and care' (Bridgeman and Monk, 2000:14-15). Bridgeman (2000:225) provides examples of how universal laws (justice) deny individual children their rights to participate in decisions affecting their bodies (and hence care for themselves), informed by a construction of childhood 'as a period of development from a state of dependency to normal adulthood'. The parallel with state control over women's bodies should not go unnoticed.

However there are problems in claiming equal rights for women and children when it is clear that the law reflects male interests, based on a universal male ethics which also protects those interests. This has led some to argue not for more rights as a solution to dependency and vulnerability, but 'a rethinking of caring relationships' (Lim and Roche, 2000). Further, Gilligan's equal but different stance in relation to gender differences and moral reasoning has been criticised for essentialising women (Nicholson, 1983) and for making a virtue out of caring when it is so rarely valued or rewarded (Ernst and Maguire, 1987). In the same way that Gilligan criticised Kohlberg of masculine bias, because he based his theory on men, she failed to theorise the effects of women's different social and economic locations by basing her theory on the voices of white, middle class, American women. Any woman failing to live up to the ethics of care she established as normative therefore would be constructed as deviant in comparison. As Young (1990:307) states:

Liberal individualism denies difference by positing the self as a solid, self-sufficient unity, not defined by or in need of anything or anyone other than itself. Its formalistic ethic of rights denies difference by leveling all such separated individuals under a common measure of rights.

Moreover the discourse of rights scripts out relations of power and inequality (Burman, 1995). Although it has been suggested that an ethics of care must theorise the needs of caregivers (Wendell, 1996:140), disabled feminists argue that the emphasis on carers' needs reinforces relationships of dependency between disabled women and their carers. (Morris, 1991). The challenge for proponents of an ethics of care therefore is to theorise different caring relationships. I now discuss what constitutes appropriate care in relation to the feeding management of disabled children and their families.

What constitutes appropriate care?

In the next section I look at how clinical practice, rather than empowering women, reproduces the discourse of blame. I then discuss the role of information in relation to risk and informed choice and the limitations of approaches that reinforce the personalisation of responsibility for decision making. I make alternative suggestions for how women can be supported when making decisions about feeding disabled children.

Good/bad mothers and the discourse of blame

Challenges to medical discourse are manifest through patient 'non-compliance' and are often attributed to the ignorance of patients (Williams and Popay, 1994). This view is predicated on an educational model which presupposes a passive patient (an empty vessel) waiting to be informed/empowered through the provision of information. Parents who do not comply with medical prescription are often seen as deviant rather than having a different perspective.

Disciplinary practices are informed by certain kinds of knowledges that are constructed as truths. Within clinical medicine evidence based practice (EBP) is promoted as a truth

while discounting other kinds of knowledge, and here lies an example of how a scientific discourse undermines clinical practice and also subverts the 'naturalised' discourse of women as nurturers. As feeding is framed in terms of 'woman's work', women are expected to know how to manage feeding. However, the discourse of women as experts is undermined by professional advice on nutrition and feeding (Tapper et al., 2003; Revill, 2002). Women are positioned as experts while their expert knowledge is undermined:

Experiential knowledge is thus dismissed and trivialised, while an arrogant, objectivising science seeks to instruct women in its own practices (Rose, 1994:37).

I have suggested that the clinical management of children has the potential to produce 'docile bodies' by requiring women to submit their feeding practices to clinical surveillance (Dayle and McIntyre, 2003). As Rose (1990:110) states, 'the ritual of the test has become central to our modern techniques for governing human individuality'. In the case of disabled children, surveillance requires that women more overtly submit their mothering to the professional gaze. This requires them to comply with a number of demands: to submit their children to various tests and investigations designed to identify pathology; to agree to the monitoring of their child's growth through various anthropometric techniques (e.g. measuring weight and head circumference) that are compared to standardised norms which define whether the child's growth is (ab)normal; to complete food diaries which monitor children's dietary intake (which is also compared to standardised norms); and, finally, to consent to the observation of their feeding practices, which may be video-recorded for further analysis or for teaching purposes. Mothers who did not submit to these procedures were differentiated and subsequently, pathologised. Mothers who did submit to these practices were also pathologised if their child deviated from the prescribed norms.

It is clear that women as mothers of disabled children experience conflicts around feeding. Advice about feeding is exerted through engagements with health professionals in a micro context, but women's feeding practices are also regulated by dominant discourses of mothering/nurturing which conflict with clinical discourses (i.e. not to feed/nurture orally). Mothering and children's feeding are influenced and

regulated by a range of health professionals and other bodies with investments in feeding, albeit with different agendas, including governments, schools, consumer organisations and the food and advertising industries. The discursive production of feeding difficulties, however, individualises women's responsibility for feeding, positions them as neglectful and undermines their parenting skills. Health care professionals construct 'non-compliant' mothers as 'chaotic', 'unable to cope' or 'unable to accept the diagnosis'. Indeed the very language used - 'feeding difficulties', 'malnourishment', 'failing to thrive' - serves to reinforce the view that women are neglectful and responsible for the poor health of their child. Advice to mothers to stop orally feeding children because this is akin to 'killing' the child constructs women as murders and feeding as harmful. An act of caring is reframed as one of harming the child. Alternative advice to increase the child's calorific intake to promote weight-gain constructs women as neglectful for failing to nurture. As such women are placed in a double bind and may feel powerless in the face of an apparent no-win situation which may have serious consequences for their mental well-being.

Such institutionalised devices are strategic in that they serve a form of psychic defence (Menzies-Lyth, 1988) as professionals attempt to manage and deal with their anxieties around the issue of 'malnourished' children and the safety of oral feeding. Professionals may also feel powerless in the face of parental anger at the suggestion they could be harming their child through feeding (or not feeding enough), thereby constituting a need to devalue, rather than identify (or collude) with the parents. The suggestion that 'harm' or 'neglect' may be involved in the caring relationship is tantamount to accusations of abuse. The undermining of women through these devices may serve to displace the mother as a capable carer while simultaneously allowing the professionals to take over the caring role (Marks, 1996). In the case of gastrostomy feeding, health care is delivered predominantly by women professionals in the first instance - paediatricians, speech and language therapists and dietitians, while the final decision often rests with the (male) surgeons. Marks (1996:138) suggests women professionals can 'occupy the paternal position, colonising the provision of care within particular professional practices'.

Additionally, presenting gastrostomy surgery as a low-tech procedure- a simple case of 'placing a small tube into the tummy'- serves to dismiss women's concerns and makes them appear unreasonable for not accepting the treatment; for if the procedure is so simple and beneficial, then why resist it? I discuss discourses of blame in relation to policy issues, supporting parents and raising standards of care, which follow on from the next section.

Informed consent and decision making

The interview study identified a number of information gaps in relation to surgical procedures and the use and management of gastrostomy feeding technologies in the context of everyday life. For example, parents (and indeed some community practitioners) did not always understand the rationale behind the surgeon's choice of gastrostomy tube. In some cases parents had expected one kind of device only to find their child had a different type of tube when they returned from the operating theatre.

Given the after-care and management of gastrostomy tubes depends on the different types of devices inserted, information and choice would seem to be an important issue; for example, some devices need to be replaced every two years on an in-patient basis, under general anaesthetic, whereas others can be replaced by a community nurse or parent every 4-6 months. Concerns about how the different devices might affect physiotherapy, or the lifting and handling of children, were also expressed.

However, there may be a number of reasons why parents are given neither information, nor choice, one of which relates to the power and paternalism of a medical profession that embraces a philosophy of providing information on a 'need to know' basis, and at the discretion of the individual physician. This then becomes institutionalised, as in the example where I approached a nurse to ask if there were any leaflets for parents about tube feeding. The nurse looked puzzled and suggested that as the physician provided the information there was no need, but added a proviso-'unless [the parents] were foreign or stupid'! Bewley (2002) quotes Morgan (1986) on the concept of 'boundary management', which describes the way individuals or groups maintain their power in organisations through the control and interpretation of information. The lack of

transparency about clinical decision making is one example of how a professional group is able to maintain their power base.

Attempts to redress the balance of power within the medical consultation by involving families in decision making with the words 'it's up to you, it's your choice' may not necessarily be experienced as empowering. As one distraught mother said to me following a consultation: 'will someone just tell me what to do?' Some families did not want the burden of responsibility for making health-care decisions for their children which positioned them as 'unwilling collaborators' within the partnership discourse. Billig et al., (1988) suggest that the notion of parents as partners or experts is constituted at the interface of a liberal ideology and institutional structures which, as I have discussed, are characterised by hierarchies of expertise and power. Given that parents do not have the knowledge-base and experience available to doctors, they may well feel unqualified to make such decisions. The discourse of choice may undermine parental abilities to act in the absence of criteria by which to make choices (Willig, 1999; Greener, 2003).

With the notion of informed decision maker comes the notion of responsibility, which presupposes that with access to information parents and children as active consumers will exercise their right to make choices. In the case of gastrostomy feeding the onus is on the 'informed' (rational and responsible) mother to make the right decision.

Risk management has become a central feature of contemporary life, and is a dominant discourse within the NHS enshrined in government policy: 'In securing better health, people can make individual decisions about their and their families' health which can make a difference' (Department of Health, 1999:5). However, the use of the term 'people' is gendered, for it is women who are currently charged with the responsibility for maintaining the health of their families and hence the nation. The report also embodies concerns about the loss of faith in expert knowledge with its emphasis on teaching people how to evaluate risk. Beck (1992:87-88) suggests this loss of faith is reflected in the transition from an industrial to a risk society. Whereas industrial society was structured by social class, risk society is characterised by greater individualisation. Appeals to science to provide solutions to problems, he suggests, is

paradoxical given science has become part and parcel of creating risk. In the face of these apparent contradictions, and loss of faith in expert knowledge, people look to themselves to craft their own risk biographies becoming 'the centre of their own planning and conduct of life'.

The 'education through information' model, therefore, is premised on the notion of the individual as a rational decision maker and fails to look at the complexity of the different discursive positionings available to women within contemporary discourses of mothering, as well as the economic conditions that are masked by the focus on the individual mother/family. Moreover, it is difficult to see what constitutes the 'right choice' when there are different and conflicting rights for children and their families, and where information is contradictory, selectively given or withheld, and structured according to professional and disciplinary resource agendas.

Further, risk assessment, rooted within individualist, behavioural models, fails to reflect that clinicians and parents have different risk perceptions, informed by different ethical stances, and that risks are part of 'cultural universes of pleasure or enjoyment' (O'Brien, 2002:290), and I have indicated how women's accounts constructed the intimacy around feeding as a source of pleasure. Women's decisions are therefore rooted in the material context of mothering and not just in their thinking, as behavioral models suggest (Currie, 1988). Behavioural models are flawed because they ignore the role of material factors in determining the distribution of risks which place the poorest and most economically marginalised at greatest risk. As Crane et al., (2002:1126) note, individuals are part of 'a larger social structure which shapes their choices and behaviour in complex and often contradictory ways'.

Murtagh and Hepworth (2003:1645) criticise the concept of informed choice in decision making in their study of women and the menopause. Drawing on Foucault's concept of governmentality, they suggest the 'ethic of autonomy' and individual choice 'intensify power relations' rather than emancipate, as the 'autonomy and freedom' which underwrites the discourse 'is the technique of government'. They argue that given menopause is constructed by a biomedical discourse, then choices in relation to health care are already defined, and therefore limited (i.e. the choice is whether or not

to take HRT). The subject position this creates is 'the informed menopausal women' empowered by her doctor. Gilleard and Higgs (2000:102) note how individuals are increasingly obliged to adopt an 'appropriate technology of the self'. A refusal to engage with governmentality, they suggest, 'is to put oneself outside society and so to be 'at risk''.

Although effective information may go some way toward alleviating parental concerns, there are wider issues about the way health care is structured and delivered, and the patterns of interaction between the different health care professionals and patients, enmeshed within networks of power, which suggest that information, although desirable, may be insufficient in the absence of other radical changes.

Critical perspectives on medicine, for example, have emphasised the issue of who has 'the control and organisation of the technologies of health and illness' (O'Brien, 2002:274). This has been at the very forefront of feminist critiques of health in terms of women's control over their reproduction and reproductive technologies (e.g. Stanworth, 1987). Foster (1989) notes very few people living in poverty are likely to benefit from the policy emphasis on consumerism and choice unless accompanied by significant material redistribution.

Policy implications: Supporting parents and raising standards of care

The privileging of the doctor-patient relationship as the basis of health care 'abstracts' healthcare from its wider social context (Mishler, 1981:83). This creates a conception of medical care characterised by specialised roles and bounded by specific remits; in the case of surgeons, their remit is defined in terms of establishing the diagnosis (e.g. what kind of procedure is needed) and the surgical placement of the gastrostomy tube. This precludes an exploration of the psychosocial aspects of tube feeding a disabled child as the need for, or results of, biomedical testing becomes the focus of the consultation. Consequently, parental concerns, which are deeply rooted in the life world, are not addressed as their child moves along a care pathway dominated by technical medicine.

Parental choice may be further compromised in the face of the surgeon's preferred method of inserting a tube, and local health authority budgetary restrictions affecting the type of devices they are prepared to support, such that cost effectiveness may preclude choice. Given the in-patient stay for the insertion of a gastrostomy has reduced in recent years, and the majority of children are discharged the day after surgery, this leaves relatively little time for parents to become proficient in the use of the feeding technology, a problem compounded by bed shortages and ward closures²⁹. Although parents did receive supervised practice, many mothers spoke of leaving the hospital feeling unprepared.

The example aptly illustrates the way patient care can fail to keep pace with technological advances. The move to outpatient diagnosis, for example, may mean there is less opportunity to support families because of lack of resources. Services may only be able to provide a limited opportunity for support through counselling because of time constraints, waiting lists and the pressures to reduce them. As such, there is a way that technological advances may disadvantage patients as patient care becomes rationalised.

Guidelines are seen as a means of standardising care, and hence of protecting patients, by ironing out idiosyncratic practices and ensuring uniformity in the delivery of services. However, this ignores the different discursive frameworks that organise professional practice discussed in chapter 4. Given that guidelines also constitute a form of 'paper trail' for audit purposes, it could be argued that they serve to protect the interests of professionals rather than the recipients of care. In these terms, guidelines are constituted as a form of defensive medicine as the quality of care becomes secondary to the bureaucratic rationalisation.

It is unlikely that an experienced clinician, who can effect a diagnosis without resorting to investigations for example, would start a conveyor belt of tests given the resource implications and the increasing pressure to maximise patient throughput. Given that I

²⁹ children are not fed post operatively until after a period of between six and twelve hours.

have already suggested the application of test results appears somewhat arbitrary, and that one of my criticisms is that patient care has become over-rationalised by the use of technology, guidelines would only serve to bolster a model of care I consider to be lacking in its concerns for the socio-emotional impact of tube feeding on children and families.

What works?

If, as I have argued, measures that attempt to move medicine closer to an applied bioscience do not necessarily translate into better patient care (Mischler, 1981), what might work? Bearing in mind the provisos previously stated about information, and given the need for information was an outcome of the study, information using different media, devised by parents for parents (and similarly, for children and their siblings) which address their everyday concerns could go some way toward meeting this need. Resourcing issues are also important. I am aware of examples where the development of leaflets has been funded, but not their production or distribution. There is also the issue of who has responsibility for handing out the leaflets and responding to any concerns the leaflets may raise?

Looking at support solely in terms of the provision of information, however, may have limited effects because from a social constructionist perspective the decision to have a gastrostomy 'is not the consequence of a cost-benefit analysis based upon an individual's social cognitions but rather a way of positioning oneself within a network of social meanings and significations' (Willig, 1999:112). A social constructionist approach has implications for feeding practices by highlighting that individual cognitions about feeding cannot be changed in isolation from the social context where people derive meanings; and I have argued that women's subject positions are overdetermined by ideas of mothering, the family and cultural prescriptions about feeding. However, as Weedon (1989:109) states, although a discourse offers a 'preferred form of subjectivity' its organisation implies other subject positions. This is supported by the fact that many women do elect to have gastrostomies for their children.

A discourse analytic approach would move beyond the provision of information and aim to empower women through the repositioning of the subject (Willig, 1999:147). The creation of alternative subject positionings outside of the good:bad mother, natural:unnatural dichotomies could open up new possibilities for feeding and parenting and help reframe tube feeding as an act of caring. Group work with women could provide a space to explore these ideas. Similarly, parents also suggested educational workshops would be helpful, providing the opportunity to meet with other families.

I have also highlighted how professional practice and recommendations may inadvertently reproduce a discourse of blame. Women may feel their concerns are not taken seriously when advised to persevere, which may also mirror the rejection they already feel at not having established a feeding relationship. The clinical management of women and children should challenge, and not reinforce, these discourses of blame. Discourse analysis can be used as a tool to challenge clinical practice and inform training programmes in professional education.

In discussions with clinical colleagues, they identified a role for a clinical nurse specialist in supporting parents which might go some way toward addressing 'the separation of technical efficiency from social and emotional concern' (Alderson, 1990:60). Indeed, surgical link nurses have been appointed in some hospitals (Chaplen, 1997). Similarly, a professional with an advocacy or counselling background could also support families. The need for an advocacy role has been recommended in relation to a number of other surgical procedures (Alderson, 1990). Lequerica (1992:552) discusses the importance of the professional status of advocates. As a paediatric psychologist with a doctorate she was highly regarded which enabled her to press surgeons to make their practice explicit. She does, however, raise the issue of how 'less credentialed' advocates would be treated by high status, orthodox professionals. This is particularly relevant in relation to link-workers who come from the communities they serve and are often marginalised within the health services.

Parent support groups such as 'Contact a Family' and 'Half Pint' can play an important role in advising and supporting parents and the development of parent mentoring schemes and peer advocates are an untapped resource (White, 1996; Atkinson, 1996).

However care is needed when advocating 'community initiatives' in the current climate of reduced welfare provision, as it could be argued that, unless appropriately resourced, they represent a transfer of responsibility for health from the welfare state to the community and, ultimately, women. Such initiatives are in keeping with the social cohesion model of health inequalities that informs the current Labour government's Third Way health policies. However, they have been criticised for failing to address the root causes of health inequalities, namely poverty (Muntaner et al., 1999:709).

Given the people most able to participate in community initiatives are likely to be those who are already 'socially included' (white, abled-bodied, wealthy and educated), there have been concerns that investments in social capital may exacerbate the very inequalities they seek to redress (Campbell and McLean 2002:33). Not everyone has equal access to social capital and the way people access networks of any kind is structured by relations of gender, class and ethnicity, and the well women clinics are a case in point. A lone parent struggling to survive on benefits may have few resources, material or personal, to participate in community activities, particularly in the absence of adequate child care. Factors such as fear of violence and racist/sexual assaults may also prevent access to support networks.

In advocating peer support, then, there is a danger that certain aspects of service delivery may be relegated to essentially untrained and unresourced parents and, ultimately, women. Further, these initiatives may actually deny access to those most in need of services. The interface between the clinical and parent support services would be an important consideration.

What constitutes 'appropriate' research practice?

In the next section I discuss what constitutes 'good' research practice. Continuing with the themes raised earlier about children's rights I discuss some of the ethical issues involved in research praxis. I explore how researchers and families can be supported in participating in research endeavours, and finally I address issues around feeding back the results of research to participants and clinicians.

Doing research: supporting families and researchers

In chapters 4 and 5 I highlighted some of the dilemmas of carrying out research in a clinical setting where care was compromised by dominant research discourses. Biomedical ethics provides for this under the principle of 'beneficence', which holds that 'research is ethically acceptable if the benefits it offers outweigh its potential for harm' (Murphy et al., 2003:151) and I have already discussed how universal, detached ethical rules can work against both women and children.

A number of researchers have discussed the adverse psychological effects of taking part in medical research (Oakley, 1992; Snowdon et al., 1997) and conclude that participants may need ongoing support to participate in research activities which should be built into the research. Featherstone and Donovan (1998) found that patients taking part in a clinical trial had a poor appreciation of the concept of randomisation and recommended that patients be given the opportunity to discuss treatment allocations. Henwood and Pidgeon (1994:226) argue that the impartial, disinterested model of research is not only incompatible with a feminist vision of egalitarian working practices but with anyone whose work is guided by an ethic of care.

However, I would argue that the conflation of care and research is further complicated by the funding of teaching hospitals and the increasing pressure to ensure treatments are clinically effective and grounded in an evidence base. The funding of hospitals and universities is increasingly dependent on teaching and research activities of which higher degrees form a part. Indeed higher research degrees are considered as an output by funding bodies, and one of the criteria used to assess research in terms of 'good value'. Under these sorts of pressures it is unclear whether junior researchers on fixed term contracts would have the power to subvert dominant ethical codes except on an individual level, as I attempted to do, rather than at an institutional level.

Further, it is difficult to see how the 'human' involvement aspect of support could be reconciled with positivist philosophies of detachment and objectivity where treatments are randomised and presented blind. I would remain skeptical that either funders, or the medical establishment, would consent to such a proposal. In the mean time the

provision of support will fall on predominantly female researchers, on limited duration contracts, who will also need support in the form of clinical supervision. Models of research embodying principles of a situated ethics, which take into account the effects of research practice on participants, opens up debates about alternative ethical frameworks and support (Vivat, 2002).

Reflecting on my own support needs, I identified four major areas that attend to the importance of separating academic and clinical supervision. The first concerns how researchers deal with the difficult feelings and emotions that working with families with sick children may evoke. Models of supervision involving psychotherapeutic practice have been recommended for researchers in dealing with the complex interpersonal dynamics encountered in relational practice (e.g. Bingley, 2002; Bondi, 2002), but in general, models have not been sufficiently developed and it is clear that different models will be required depending on the individual needs of researchers. Whittaker (1995) recommends the need to budget for independent supervision when applying for grants, and suggests a role for ethics committees in ensuring mechanisms are in place to support researchers.

The second area concerns research and project management skills and how researchers can be supported in directing externally funded projects through to completion. The third area relates to staff management and the support needs of researchers working in a supervisory capacity. Researchers often have to support and supervise other staff, who have very little research experience themselves. Given the need to meet deadlines, this can present its own demands on researchers. Power relations within research teams is another taboo subject which also needs to be theorised (Kelly, 1994; Roberts, 1981). In addition to training courses to equip researchers with project and staff management skills, peer support through research networks can be an invaluable resource. In action research, action learning sets have also been used as a non-directive means of supporting researchers through learning (Johnson, 2003).

Finally, there are issues about the lack of services for families and how this impacts on researchers in trying to meet their needs. Researchers may be required to adopt a developmental role, that is, to act as a change agent and work toward the development

of services for families. However, development work requires a different set of skills to those considered necessary for research. Development work also has resource implications, both institutional and personal, in addition to disciplinary commitments towards developing services³⁰. Research supervision is clearly an aspect of the research process that needs to be brought to the attention of the funding bodies that commission research, and the academy. My experience also raises issues about PhDs, constituted as part of externally funded studies, and how their 'ownership' influences the type of approaches and analyses researchers adopt, and the conflicts that arise as a result of trying to satisfy different agendas and audiences.

'Feeding' back: unsatisfactory endings, new beginnings

At the end of the clinical evaluation we were required to write a report to the funding body (August 2002). However, with the restriction of a 5,000 word limit (and it has taken me some 95,000 words in this thesis to try and convey something about the meanings women attach to feeding and attests, perhaps, to the discursive construction of research reports and the doctoral thesis, governed by word limits, rules and regulations), I opted to give the funders what they had initially asked for – 'a few sentences from parents' (see Chapter 1). I then included a final paragraph in the report stating that some of the issues raised would be explored further in a PhD. However, I felt that in privileging narratives of feeding constructed through an experimental discourse, I had somehow been forced to collude in the suppression of other narratives. Discourse analysis is imbricated in ideology and power, and goes beyond identifying discursive configurations to identifying their 'ideological functions and effects' (Henwood and Pidgeon, 1994: 235 quoting Michael, 1991). Inductivist analyses necessarily fall short of identifying the regulatory aspects of infant feeding practices.

Ironically, following the external peer review of the research report one of the referees commented:

³⁰ I am grateful to Angela Cotter at City University, London for facilitating my thinking around these ideas.

Some of the most informative findings were obtained from the verbatim comments rather than from scales and checklists, the latter giving helpful information re the nature of the study sample but less sensitive and informative in detecting difference and change. The reviewer wondered whether you would use or recommend to others the use of more sophisticated qualitative methodologies in future work of this nature.

Working within medical institutions on short-term contracts funded by external grants, researchers like myself are often wary of presenting our work to mainstream audiences. Qualitative research has curried favour in some health settings. However, I certainly never contemplated standing in front of an audience of surgeons and announcing that I was conducting a critical feminist discourse analysis. Rather my presentations were crafted pragmatically toward the different kinds of professionals in attendance. A medical colleague of mine once expressed his concern that important aspects of my work would not reach the medical establishment because I was more likely to publish the controversial/illuminating aspects in journals for the social sciences.

To some extent this is true. However, there are structural constraints which also deter us, as well as a fear of rejection. For example, at one paediatric conference I was given ten minutes to present the qualitative study (two minutes were for questions). Further, for our own career pathways we need to publish in different types of journals that reach both a clinical and a social science audience, which may not always be compatible. Multi-disciplinary research therefore is not without its problems, but perhaps we should feel encouraged by the words of external reviewers and medical colleagues to go forth and do our preferred form of research and analysis and present it in the mainstream rather than furtively in the (relatively) safe guise of a PhD.

Another unsatisfactory ending was that as my contract came to its conclusion, there was no time to disseminate the findings to parents and get their feedback. Apart from the lack of time, I also had a concern that communicating findings by newsletter or article could prove problematic. It seemed a very impersonal way of relating to parents. How would I explain the complex terminology involved in discourse analysis or biomedical research? How would parents respond to the statistics indicating that a percentage of children had gained weight and yet their child was one of those who did not for reasons that were poorly understood? What if a child was currently very ill? Some of the

children would have died, which can always be checked through hospital computer systems, but given the risk of critical illness with this group of children, the newsletter approach felt unsatisfactory.

In an ideal world of permanent posts, where a culture exists in research practice to ensure time for the appropriate dissemination of findings, researchers might consider fun day events as a way of communicating findings. Such events would need to be adequately resourced with transport and food provided and activities for the children, for example, massage and play-workshops. Group work with parents could be accommodated as part of the day, with parental presentations, which would go some way toward diluting the researcher/researched, professional/parent dichotomies, and might counter some of the problems of how researchers represent families' experiences. I am aware of a disjuncture between the 'distinctive voices' in the interviews with women and the academic style of writing in this thesis. Some researchers have written books for lay readers in addition to outputs for academic audiences in order to counter the academic discourse which often renders 'research findings inaccessible' (Roberts, 1981). Inviting women to write about their experiences as co-authors would take this a stage further.

A crucial aspect of the research cycle was therefore left incomplete because of uncertainties about my own financial future and time constraints. This illustrates that although I may have occupied a privileged position in academia, and in relation to the study participants, this was short lived (although I again find myself back in academia on another fixed-term contract). It highlights the problem of focussing on researcher positionality, with its emphasis on the 'micropolitics' of research practice, without due regard for the 'macropolitics in societal inequality' (Lal, 1996:197) which has material effects for both researchers and participants.

Clinicians are all too aware of parental attitudes toward tube feeding. It is perhaps ironic that the research was convened to legitimate many of the clinician's own observations that gastrostomy feeding was beneficial but often met with parental resistance. However, clinical observation is no longer seen as admissible as 'p' values become the accepted way of understanding outcomes in a neat and tidy fashion. In

some ways my research has reflected back the complexity of feeding decisions and left the story untidy. Unfortunately, none of the clinicians involved in the study were present, due to timetabling difficulties, when I fed back my final conclusions. This again left me feeling dissatisfied and cynical about who the research was for, who would benefit from it, and in what way?

Reflections on feeding

'If I can't feed and cuddle him what else can I do? [mother, exit interview]

In this section I reflect on feeding relationships, intimacy and power. The insertion of a gastrostomy involves a recoding of the body and requires women to renegotiate their relationships with their child. I speculate on what it means to no longer be the sole feeder, and what women feel they are 'giving up' when they 'give in' to tube feeding. Having sole responsibility for feeding can be experienced as stressful, but at the same time, places women in positions of power. Some women may have fantasies about being the sole feeder and feeling needed. This power may mirror the powerlessness they face with regard to other aspects of their lives, including, perhaps, the uncertain developmental trajectory of a disabled child, over which neither parent, nor professional, has any control. Women may not experience mothering as exploitative (Carby, 1987), and may derive a great deal of pleasure from children. 'Babies can make women feel wanted and needed' (Walkerdine and Lucey, 1989:156): dependency can be appealing only to change once a child grows up. Many disabled children however remain dependent and have a form of prolonged babyhood, which can also appeal and fill needs.

Parents, and women in particular, have enormous responsibility for children but can be almost completely disempowered in the face of illness or death. The only certainty about a child with a rare disease, or a life-limiting condition, is that at some point they will die, prematurely. Parents are rarely prepared for what to expect. James and Prout (1990:245), summarising the work of Myra Bluebond-Langner (1978) on dying

children on a cancer ward, note the contradictory images of children as signifiers of the future and sick and dying children:

The contemporary ideology of childhood which locates its importance firmly in the future is violently disrupted by the development of terminal illness during childhood.

Marks (1996:131) comments on the way childhood has come to represent a 'lost era of innocence', such that when 'children violate categories of innocence they disrupt adult investments and desires to return to a (mythical) past'. Children who have been sexually abused, who murder, or who are sick and disabled, fall foul of the idealised constructions of childhood, are deemed deviant, and are therefore excluded. However, children who are sick, or disabled, cannot be blamed for their situation in the way children who murder, or are sexually abused, are rendered culpable (Kitzinger, 1990).

Children who have spent much of their lives ill and hospitalised are often seen as having had their childhood (innocence) stolen away from them. It is possible that women compensate for the guilt and powerlessness they feel by 'over-adjusting' to the feeding situation as a form of 'coping', as a way of giving back that stolen time, of reinstating the child. This could perhaps account for the desire to feed orally when it has been established that this would be unsafe, or why a mother cherishes feeding an older child on her lap when this would not be considered age-appropriate with a child that was not disabled. Anxieties about the loss of sensuality around feeding and intimacy may be at stake.

Women take their cues about what is appropriate behaviour for a mother from prevailing discourses and ideology. For example, mothering in Western culture is iconified by two dominant discourses, Judeo-Christianity (the Pieta) and medical discourse (Woodward, 1997). The madonna and child, as an idealised image of motherhood, may permeate women's own fantasies about mothering, and being mothered. As Woodward states: 'Myths can offer idealised images of perfection to which we should aspire' (1997:250). Women may locate the site of this idealisation within the feeding relationship and project their own experiences of how they were mothered, or would have liked to have been mothered, onto their own relationship with

their child. Women's anxieties around feeding may relate to the perceived threat of disruption and displacement of this idealised image. Once the idealised image of the good mother has been displaced, this only leaves the monstrous mother to fill the void.

When I first started my job, one of the neurologists told me parental opposition to gastrostomy related to their 'inability to accept the diagnosis'. The problem I initially had with this view was the way it problematised individual parents for having failed to 'adjust'. Conversely, the 'responsible' parent who accepts the diagnosis resonates with the rhetoric of mental hygiene (Goffman, 1990:140) and governmentality. Four years later, a psychology colleague summed up my attempts to explain the complexities involved in feeding decisions in one short sentence – 'well it's about parenting, isn't it?' In the same way that this sentence did not reflect the process of my deliberations (it had incidentally taken me some three years plus to arrive at these conclusions), it did not reflect the process of women's deliberations either. Yes, gastrostomy feeding is about parenting (mothering), but it is also about much more, including the aspirations parents have to give their children the best quality of life possible. It sheds light on the intimacy of feeding relationships, sensuality and power (as evidenced by the scenario of the mother feeding an older child on her lap when this is not considered appropriate - although we might question why this is considered prohibitive beyond a certain age), and enjoying that special time together. The period of physical intimacy around feeding is curtailed in the non-disabled child as soon as she is weaned, or can self feed. It would be interesting to analyse women's accounts of breastfeeding older children in order to understand more about the investments in feeding and intimacy, bearing in mind that women who continue to breastfeed toddlers for example, are often pathologised as unnatural (Burchill, 1999).

Of the older teenage children, the growth promoted by gastrostomy feeding dramatically changed their physical appearance in some cases. My own observation was that the growth ascribed a sexuality which had previously been masked. I noticed how one girl had 'physically' matured into a young woman. She now wore her hair short with highlights (the pig-tails and ribbons were gone). Another boy looked stocky and muscular whereas before he was thin and child-like. There are therefore issues about caring, intimacy and children's 'emerging' sexuality and how parents experience

and manage these changes which I did not explore. A study with an older group of children, although practically difficult given many children have gastrostomies inserted at a much earlier age, would cast light on some of these issues. It would also be interesting to carry out a longer-term follow-up study of this cohort to see whether women changed their feeding practices and how they account for the change.

In this thesis I have illuminated the structural and psychic investments in feeding non-disabled as well as disabled children. Whereas the biomedical body is read as an object in need of repair in order to grow and be healthy, women read their child's body in terms of different symbolic meanings constituted through feeding. I have suggested broader connections around mothering and feeding in general, with feeding disabled children in particular. I have illustrated that feeding represents much more than obtaining an adequate nutrition and suggest that interventions aimed at supporting women that emphasise the nutritional aspects of feeding, may well miss the point. Feeding disabled children blurs the 'boundaries' between mothering and caring. The mothering role becomes displaced on to that of professional carer - nurse, physiotherapist and finally, pedagogue - suggesting women are more than 'just' mothers. The different functions women perform need to be acknowledged and the policy implications theorised.

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Appendix 1:Aims of the interview study

Title

What are the issues caregivers face with respect to making decisions about the feeding management of children with neurodevelopmental disabilities

Aim

- i) to describe parental experiences of feeding, both tube and oral
- ii) to identify the type of issues parents take into account when making decisions about the feeding management of children and make suggestions for how families can be supported

Objectives:

- to describe the context within which parents decide to have a surgical gastrostomy feeding tube for their child
- to examine the reasons parents give for their opposition to the procedure
- to describe parental experiences of gastrostomy feeding and its management post surgery
- to explore ways of supporting parents in making decisions about the feeding management of children

Appendix 2:Background to the clinical evaluation

The aim of the evaluation was to measure the immediate medical, psychological and economic costs and benefits of gastrostomy placement for children with neuro-developmental disabilities and their families with a view to identifying predictors of positive outcome and complications of the procedure. It was hypothesised that gastrostomy feeding would:

- i) improve the physical health of children with developmental disabilities
- ii) improve nutrition
- iii) result in catch up physical growth
- iv) reduce the burden of care and stress associated with caring for the disabled child

The experimental design originally proposed, a simple pre-post test (that is, with a single measurement before and after gastrostomy), was considered to be 'weak' by the Commissioning advisory group who suggested 'strengthening' the original design with the incorporation of additional time points for assessment. The research design proposed was a controlled experimental study where each child acted as his or her own control while on the waiting list for surgery providing a pre-operative baseline with which to compare post-operative outcomes. Although a randomised control trial (RCT) would have been the preferred choice for a treatment evaluation, on the basis of clinical experience, the withholding of a potentially beneficial treatment in order to allocate children to a control group was ethically difficult to justify. Subsequently the additional time points were incorporated and children and their families would be assessed four times, twice before and twice after surgery at standard intervals. The rationale of the study being that any changes experienced post-operatively would be greater than those witnessed pre-operatively (the control period).

Inclusion criteria

The inclusion criteria were children:

- presenting for a gastrostomy +/- antireflux procedure (ARP)
- presenting with non-progressive brain damage with motor involvement, including oro-motor problems
- who were developmentally delayed

Children were included if they presented with the following diagnoses:

- cerebral palsy
- a chromosomal abnormality (eg. Down's syndrome)
- a named syndrome (eg. Noonan's, CHARGE)

Children whose feeding difficulties were attributable to other systems failure (eg. renal problems, cystic fibrosis, epidermolysis bullosa) were not included.

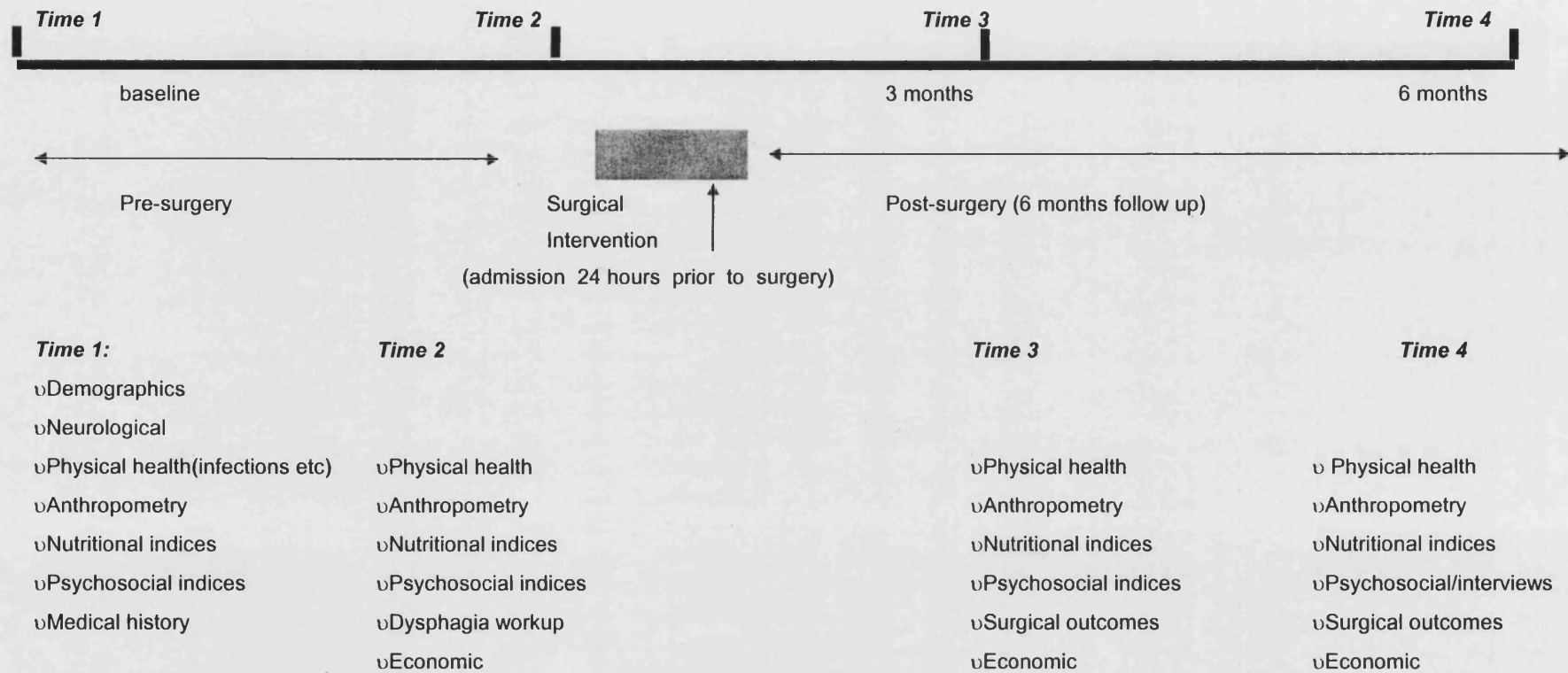
Outcome measures

The following outcome measures were used and are described in more detail in the results section:

- Anthropometry (weight, mid-arm circumference, height)
- Nutritional indices (biochemical indicators, five-day prospective food diaries)
- Health indices (biochemical indicators, parental reports)
- Surgical (eg. complications of the procedure)
- Economics (costs associated with the procedure)
- Psychosocial (eg. stress associated with the demands of caring for a disabled child)

In addition to the above, the commissioners recommended a qualitative interview study.

Figure 1. Research design



Appendix 3: Interview schedule-pre surgery

Introducing the study

Reiterate right not to answer questions/terminate the interview at any time/switch off tape recorder. Ask about household composition/ significant others/other children -age breakdown

Background/referral

- Story leading up to how you came to be referred to the hospital/clinic
- What did you think the problem was?
- What sort of solution/help were you looking for?
- What were you told the problem was, by whom, when
- What sort of suggestions did staff make about how to help [name of child]
-prompt referral or NG tube suggested

Mealtimes and feeding

- Can you describe a typical meal with [name of child]
- Good day/Bad day
- Time spent feeding

Attitudes

- Thinking back to when it was first suggested that [name of child] may need assistance with feeding:
- When was this first suggested to you/ by whom?
- What were your reactions/feelings then?
- What were the reactions of other members of the family? [partner, relatives, friends]
- What about now?
- Can you tell me in what ways you think a gastrostomy might help [name of child]?
- What about you, your partner, other members of the family

Decision and choice

- How many appointments have you had where a gastrostomy has been raised/discussed with you (with whom)?
- How long did it take to make the decision (months/years)?
- How long did it take between making the decision and getting things moving?
- Who has been influential in helping you to arrive at a decision about whether or not [name of child] is going to have a gastrostomy?
-prompt staff, other parents, self help groups
- How useful were these and in what ways?
- In reaching a decision about what to do, what sort of factors have you taken into account?
- Do you feel you have had a choice about whether [name of child] has the gastrostomy or not?
- Can you describe some of the ways in which you feel you have been involved in the decision/have not been involved in making the decision about whether [name of child] should have a gastrostomy?

Support

- What help/support do parents need when making a decision about their child's nutrition?more specifically in relation to gastrostomy
- How could service delivery in general be improved to help parents make the right decision for their child?

Closing the interview

Is there anything else you would like to add about what we have discussed today?
Thank you for sparing the time to talk to me today. As we discussed I would like to come back and talk to you in 3-6 months time, but only if you agree. Again I would like to say that you are under no obligation to take part in a further interview, this is entirely your choice.

Appendix 4: Interview schedule –follow up

- **Experiences of feeding**
 - **Discharge from hospital**
 - **Using /managing equipment**
 - **Feeding regimes**
- **Advantages/disadvantages of tube**
 - **For child**
 - **For family**
- **Child health**
 - **sleeping/temperament**
- **How tube fits in with everyday routines**
 - **School**
 - **Respite/care**
- **Qualityof life issues**
 - **Parents/family**
 - **Child**
- **Right decision**
 - **For child**
 - **For parents**
- **Support**

How can parents be supported in making the decision?
- **Experiences of taking part in the research**

Appendix 5: The QRS-F

(Questionnaire on Resources and Stress- Friedrich Short Form - Pessimism and Family problem scales taken from McConachie, H. Waring, M. (1997) Parental Coping and Support, In: Sclare, I. (eds) *Child Psychology Portfolio*, Windsor, UK: NFER-NELSON

The following statements deal with your feelings about your child with multiple and complex needs. There are many blank spaces on the questionnaire (_____). Imagine the name of your child in each of these blank spaces. Please give your honest feelings and opinions. Respond to all of the statements, even if they do not seem to apply. If it is difficult to decide "true" or "false", answer in terms of what you or your family feel or do *most* of the time. Sometimes the statements will refer to difficulties that are not applicable to your family. These statements can still be responded to with a "true" or "false". Please respond to all of the statements by circling either T (TRUE) or F (FALSE).

TRUE FALSE

| | | |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | 1. Other family members do without things because of _____ |
| <input type="checkbox"/> | <input type="checkbox"/> | 2. Our family agrees on important matters. |
| <input type="checkbox"/> | <input type="checkbox"/> | 3. I worry what will happen to _____ when I can no longer take care of him/her. |
| <input type="checkbox"/> | <input type="checkbox"/> | 4. Constant demands to care for _____ limit the growth and development of someone else in our family. |
| <input type="checkbox"/> | <input type="checkbox"/> | 5. I have accepted that _____ might have to live out his/ her life in a special setting (e.g., group home, institution) |
| <input type="checkbox"/> | <input type="checkbox"/> | 6. I have given up things I really wanted, to care for _____ |
| <input type="checkbox"/> | <input type="checkbox"/> | 7. _____ is able to fit into the family social group. |
| <input type="checkbox"/> | <input type="checkbox"/> | 8. In the future, our family's social life will suffer because of increased responsibilities and financial stress. |
| <input type="checkbox"/> | <input type="checkbox"/> | 9. It bothers me that _____ will always be this way. |
| <input type="checkbox"/> | <input type="checkbox"/> | 10. I can go to visit friends whenever I want. |
| <input type="checkbox"/> | <input type="checkbox"/> | 11. Taking _____ on holiday spoils pleasure for the whole family. |
| <input type="checkbox"/> | <input type="checkbox"/> | 12. The family does as many things together now as we ever did. |
| <input type="checkbox"/> | <input type="checkbox"/> | 13. I get upset with the way my life is going. |
| <input type="checkbox"/> | <input type="checkbox"/> | 14. _____ doesn't do as much as he/ she should be able to do. |
| <input type="checkbox"/> | <input type="checkbox"/> | 15. There are many places where we can enjoy ourselves as a family when _____ comes along. |
| <input type="checkbox"/> | <input type="checkbox"/> | 16. _____ is over-protected. |
| <input type="checkbox"/> | <input type="checkbox"/> | 17. _____ has too much time on his/ her hands. |
| <input type="checkbox"/> | <input type="checkbox"/> | 18. I am disappointed that _____ does not lead a normal life. |
| <input type="checkbox"/> | <input type="checkbox"/> | 19. Time drags for _____, especially free time. |
| <input type="checkbox"/> | <input type="checkbox"/> | 20. It is easy for me to relax. |
| <input type="checkbox"/> | <input type="checkbox"/> | 21. I worry what will happen to _____ when he/ she gets older. |
| <input type="checkbox"/> | <input type="checkbox"/> | 22. I get almost too tired to enjoy myself. |
| <input type="checkbox"/> | <input type="checkbox"/> | 23. There is a lot of anger and resentment in our family. |
| <input type="checkbox"/> | <input type="checkbox"/> | 24. Constant demands to care for _____ limit my growth and development. |
| <input type="checkbox"/> | <input type="checkbox"/> | 25. I feel sad when I think of _____. |
| <input type="checkbox"/> | <input type="checkbox"/> | 26. I often worry what will happen to _____ when I can no longer take care of him/ her. |
| <input type="checkbox"/> | <input type="checkbox"/> | 27. Caring for _____ puts a strain on me. |
| <input type="checkbox"/> | <input type="checkbox"/> | 28. Members of our family get to do the same kinds of things that other families do. |
| <input type="checkbox"/> | <input type="checkbox"/> | 29. _____ will always be a problem to us. |
| <input type="checkbox"/> | <input type="checkbox"/> | 30. I rarely feel blue. |
| <input type="checkbox"/> | <input type="checkbox"/> | 31. I am worried much of the time. |

Appendix 6: The Daily Living Scale

The following statements relate to parents' experiences of looking after their child with multiple and complex needs. There are many blank spaces on the questionnaire (_____). Imagine the name of your child in each of these blank spaces. Please read each statement and circle **one** of the ratings **1, 2, 3 or 5, 6, 7** which best describes how difficult or easy you have found this aspect of caring for your child **during the last two weeks**. Please circle **4** if you have found this aspect of caring for your child neither easy nor difficult. If any of the statements do not apply to you, please circle NA (not applicable).

| | very easy | very difficult | | | | | | | | |
|--|--|-------------------|---|---|---|---|----|---|----|--|
| Dressing _____ has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Bathing _____ has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Toileting _____ has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Calming _____ when he/ she is upset has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Feeding _____ has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Giving _____ medication has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Getting _____ to sleep has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Taking _____ out shopping has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Taking _____ out to visit relatives/ friends has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Going out with _____ generally has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Finding the time to do enjoyable things with _____ has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Lifting _____ has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| In general, physically handling _____ has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Caring for _____ in general has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |
| Others have found caring for _____ has been | <table border="1"><tr><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>NA</td></tr></table> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | NA | | | |

(Scale devised by Craig et al., 2002)